# "IT'S HARD ENOUGH FOR THE PEOPLE DOING THE WORK TO ACCESS THESE SERVICES": SEXUAL HEALTHCARE BARRIERS THAT LGBTQ2S+ POPULATIONS EXPERIENCE IN A RURAL CANADIAN COMMUNITY

# "IT'S HARD ENOUGH FOR THE PEOPLE DOING THE WORK TO ACCESS THESE SERVICES": SEXUAL HEALTHCARE BARRIERS THAT LGBTQ2S+ POPULATIONS EXPERIENCE IN A RURAL CANADIAN COMMUNITY

By RASHA TAHA, B.Sc. (Hons.), BSW

A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the Requirements for the Degree Master of Social Work

McMaster University MASTER OF SOCIAL WORK (2018) Hamilton, Ontario

**TITLE:** "It's hard enough for the people doing the work to access these services": Sexual Healthcare Barriers that LGBTQ2S+ Populations Experience in a Rural Canadian Community

**AUTHOR:** Rasha Taha, Hons. B.Sc. (University of Guelph), BSW (McMaster University)

**SUPERVISOR:** Dr. Saara Greene

**NUMBER OF PAGES:** vii, 119

## Abstract

Despite Canada's universal healthcare system, there exist numerous barriers that prevent LGBTQ2S+ populations from accessing healthcare services such as sexual health. Through pulling from community-based research principles and utilizing a critical social science framework, this research explores the availability and accessibility of sexual health services for LGBTQ2S+ individuals living in a rural Ontario community. After extensive consultations with multiple key informants, two focus groups were conducted with individuals from a community-based collaborative where members had the dual role of being service providers and community members. It is important to note that gaining access to the collaborative was made possible due to the resources and networks provided by the AIDS Network, a community charitable organization. Using a thematic analysis of the data, three major themes surfaced: the negative effects of heteronormativity, queerphobia, and transphobia within healthcare settings; barriers to accessing sexual healthcare; and community responses and strategies. These findings are reflected in the literature concerning issues of healthcare access for LGBTQ2S+ populations, but these research findings are unique given they are specific to both sexual health and rural communities. Implications for social work education, practice, and research include tapping into the potential of collaboratives; creating LGBTQ2S+-specific policies; making space for community voices, especially within academia; and recommendations for healthcare providers.

## Land Acknowledgement

The land where this research took place is on the traditional territory of the Anishinaabe, the Haudenosaunee, and the Neutral Nations.

This land is subject to the Haldimand Treaty of 1784, which guaranteed the exclusive use of nine hundred and fifty thousand (950,000) acres along the Grand River for Indigenous Peoples.

To this day, through processes of colonialism, racism and genocide, settlers have secured nine hundred and two thousand (902,000) acres of the Haldimand Tract for their own, leaving only forty-eight thousand (48,000) acres for Indigenous Peoples.

The intent in acknowledging this territory and this treaty is to recognize the many ways that settler communities have been, and continue to be, implicated in the historical and continued processes of colonization. The land on which this research took place is stolen.

## Personal Acknowledgement

First and foremost, I would like to thank the person who has stood beside me throughout this entire whirlwind of a journey while going through her own rollercoaster ride. Thank you, Doyi, for making sure I still made time to have fun even when anxiety and work were overflowing, for being my adventure buddy, for tolerating the cats even though their fur makes you sneeze, for always being down for coffee breaks, and for pushing me past my comfort zone (fully knowing how small that place is). Saranghae, bhibbik.

To my MSW Critical Analysis classmates, thank you for all the validation & never-ending support. I'm rooting for you all to find your dream jobs!

To Jennie, thank you for being extremely flexible with your schedule, for letting me vent to you about writing, & for making a job a fun process. You rock.

To my supervisor, thank you for your guidance, for believing in my potential, and never settling for anything less than excellent. I have learned a great deal from you over the past year, and I hope our paths cross again in the future.

To my family, thank you for dealing with me through thick & thin. I hope I can make you proud with this degree.

To the participants of this research, none of this could have materialized without you. Thank you a million times over for trusting me with your stories of pain and resistance. This research is yours.

## Table of Contents

# Chapter 1: Introduction

## 1. Prologue

As a queer, able-bodied, white-passing immigrant person of Middle Eastern descent, the way that I experience the world is largely shaped by the stories I grew up with. Stories of belonging, of being ousted or shunned, and of being different all influence my worldview and how I navigate society. These stories have widened my perspective on what it means to exist in this world, and that there is no one prescriptive way of belonging to a community. My own journey of belonging has been turbulent and rife with struggles, but it has helped me better understand other people who are either walking a similar path as myself or are diverging onto a separate one entirely. In my quest for understanding who I am as a queer social worker living on Turtle Island, I came across oppositions to how my multiple identities intersect and interact with the world, namely arguments that homogenize a queer person's experience as one particular kind of experience. Alternatively, I came across narratives of how Middle Eastern immigrants ought to live out their lives. What I did not see often, however, were narratives of how the intersections of those identities -and others- could exist in the world. That not only enraged me but set me back on my journey significantly; how could I exist in this world if this world does not see people like me?

This research is about belonging, resisting, and persisting. It is about people who do not fit the mould that society expects them to fill. It tells stories of people who have found creative ways of navigating a society that rejects who they are. It also tells stories of people who fall through the cracks when they try to ask for help. This research brings out stories of deep inequity and oppression, but it also highlights strategies of resistance and innovative tactics. Most importantly, this research relied on a number of community members working together to tell these stories. None of this research could have come about if it was not for collaborative efforts between multiple stakeholders who were invested in the outcomes. My role was to organize and compile the data in ways that made sense, but I did not do more than simply report on what was happening in the community. As such, this research does not belong to me, but belongs to the community.

## 2. The First Step

This research would not have been entirely possible if it was not for impeccable timing. In the summer of 2017, I was getting anxious thinking about what my Masters thesis topic would be on. I knew I wanted it to be specific to the lesbian, gay, bisexual, transgender, queer, two-spirit (LGBTQ2S+) populations, but was not particular about how. I decided to email a previous community-based research (CBR) professor of mine, Dr. Greene, whose work I had admired and ask if she was taking on any MSW students. We then scheduled a phone call and she told me how she wanted to take on a couple of students to work on the development of an evaluation for the AIDS Network. Given the population that utilize the AIDS Network, she thought that it would be possible to include my interest in doing research that reflects the needs of LGBTQ2S+ individuals. I enthusiastically agreed to be a part of the project and to meet with the AIDS Network in October to discuss the details. While the research question was developed over a series of multiple consultations and meetings spanning several months, it is important to note that my MSW research was a small part of the AIDS Network's larger research and evaluation process that was funded by the Public Health Agency of Canada. My research question, which I hope will be used as part of the larger evaluation, is: what kinds of barriers to sexual healthcare do LGBTQ2S+ individuals living in a rural setting experience, and what are the ways in which they resist or overcome these barriers?

As far as CBR projects went, I was unsure how I would implement a CBR project within the scope of eight research-active months. While I had never officially 'done' CBR, I had read and thought about its many principles extensively, and I had not come across any projects that were completed within a year's timeframe. Nonetheless, I was hopeful that Dr. Greene would help me find tactful ways of incorporating CBR principles into my research. What I had not fully anticipated were the numerous obstacles I would encounter due to the ever-changing nature of community work. I quickly realized that having limited clarity of the scope of a CBR project is a common theme in this type of research, since the project itself is moulded by different stakeholders across several meetings and consultations. For example, I could not decide on a data collecting method since the individuals I was consulting with were themselves unsure of how they wanted to communicate their knowledge, prolonging that decision-making process across three separate meetings. While I had always theoretically known that this type of research was created neither by me nor for me, I was unaware of what that had genuinely meant experientially and on the ground. It meant that it would take me about three to four meetings with two different people to get some sort of idea on what my research question would look like; another four to five meetings to start building relationships with key informants in the research; and three or so more meetings to be able to identify how to best go about the research. This is besides trying to decide on a time and date to do the focus groups. Nonetheless, this type of project cannot be done without building relationships with the people who are key players in shaping the research, and that is not something that occurs overnight. Overall, I have no regrets in choosing CBR as a method to conduct this research, as what it has brought forth far outweighs its struggles.

## **Chapter 2: Literature Review**

Despite claims that the public health system in Canada is at the forefront of progressive legislation that is specific to issues concerning the health and well-being of LGBTQ2S+ communities, both activists and scholars argue that it falls short of ensuring that these vulnerable populations have access to appropriate, accessible, and safe healthcare (Mulé, 2005; Mulé, Ross, Deeprose, Jackson, Daley, Travers, & Moore, 2009). Importantly, as argued by Mulé (2005), LGBTQ2S+ communities continue to experience barriers to healthcare as a result of heterosexism and transantagonism. It should be noted that, in this research, transantagonism and transphobia are words that are used interchangeably, as are gender non-conforming and non-binary.

The stigmatization and discrimination of LGBTQ2S+ populations can lead to barriers to accessing safe and appropriate mental health and reproductive health care, as well as experiences of higher rates of diseases and ailments (Mulé & Smith, 2014). When it comes to sexual health, sexual stigma negatively impacts the health and wellbeing of LGBTQ2S+ individuals, especially since sexual health is not a topic that is often discussed or brought up in a healthcare setting. When sexual health issues are brought up in healthcare settings, there is evidence demonstrating that LGBTQ2S+ individuals are likely to experience negative repercussions due to their sexual orientation or gender (Hubach, Currin, Sanders, Durham, Kavanugh, Wheeler, & Croff, 2017). This is because there is a lack of culturally competent healthcare providers who are knowledgeable about LGBTQ2S+ health, which can then result in barriers to accessing healthcare due to fears about accessing care or because they have been refused care (Lim, Brown, & Sung Min, 2014; Keuroghlain, Ard, & Makadon, 2017; Scheim & Travers, 2017).

As someone who identifies as a part of the LGBTQ2S+ community, I am particularly interested in understanding why people like myself fall through the cracks when it comes to sexual healthcare, especially given this community's vulnerabilities. This research involves looking at the availability and accessibility of sexual health services for LGBTQ2S+ individuals living in a rural part of Ontario, and it is not surprising that this intersection of queerness, rural living, and sexual health does not yield much research within the Canadian context. In the following literature review, I will discuss what is already known about access to sexual health services for LGBTQ2S+ communities both broadly and for those living in rural communities, identify the gaps that exist in our current knowledge of this topic, and how this current MSW research can contribute to the knowledge base in this area.

## 1. Barriers to Sexual Health Services

Given that most of what we know about access to sexual health services for the LGBTQ2S+ community has been conducted in urban settings, there is very little known about how these issues play out for this community within rural or remote settings. Research that has been done in rural and remote settings argues that these issues, such as heteronormativity and lack of healthcare practitioner knowledge, will be multiplied in rural settings that are often more conservative and present more barriers for vulnerable populations. Other than sexual stigma and the pervasiveness of heteronormativity, some of the more rural-specific issues affecting LGBTQ2S+ populations' sexual health include the effects of religion on the local culture and a lack of education and awareness raising regarding LGBTQ2S+ sexual health (Hubach et al, 2017; Hubach, Dodge, Schick, Ramos, Herbenick, Li, Cola, & Reece, 2015). Since most research on the experiences of LGBTQ2S+ individuals focuses on urban settings, rural queer experiences are then often made invisible and thus irrelevant (Marple, 2005). Studies that focus on the sexual health needs and experiences of LGBTQ2S+ populations often conduct their research within an urban setting, and even then, the lack of services and queer and trans antagonism are still prevalent issues (Scheim & Travers, 2017; Muscolino, 2016). One of the most widely known realities facing LGBTQ2S+ populations globally is that they are at increased risk for and vulnerable to sexually transmitted infections (STIs) and of HIV (Campbell, 2013; Scheim & Travers, 2017; Hubach et al, 2017; Keuroghlain, Ard, & Makadon, 2017). Moreover, the literature also suggests that the reasons as to why there is this increased risk is the result of discrimination in the form of heterosexism and transantagonism, a lack of understanding of sexual health needs of this population, and almost non-existent LGBTQ2S+ health education for health practitioners. Moreover, transgender and non-binary populations are consistently placed at elevated risks of discrimination in healthcare settings more so than LGB communities (Scheim & Travers, 2017; Lim, Brown, & Sung Min, 2014).

Due to the uneasiness associated with sexual health in general, especially in more conservative rural settings, bringing up LGBTQ2S+ sexual health may not be comfortable or even welcome, depending on the capacity of the healthcare provider. Moreover, the literature has also shown that even one negative experience with a healthcare provider as an LGBTQ2S+ individual can result in a decreased possibility of returning for services or treatment (Carrotte et al, 2016; Hsieh & Ruther, 2017; Lim, Brown, & Sung Min, 2014; Scheim & Travers, 2017). This puts LGBTQ2S+ individuals at high risk of potentially treatable diseases; specifically, for transgender and non-binary individuals, barriers to accessing healthcare services have been described by Lim, Brown, & Sung Min (2014) as having "catastrophic consequences". According to Hubach et al (2017), sexual health stigma deterred men who have sex with men (MSM) from seeking out important sexual health information. This raises important implications when taking into consideration the ways that queerphobia, transphobia, and heteronormativity impact members of LGBTQ2S+ communities more broadly, suggesting that they will find it even less appealing and more harmful to seek out sexual health services in rural areas.

### *a. LGBTQ2S+ in Rural Settings*

Unfortunately, the literature is rather scarce when it comes to discussing LGBTQ2S+ sexual health within a rural setting. While there are numerous studies that discuss LGBTQ2S+ lives within rural settings, discussions around sexual health and access to those resources are not common. Out of the few studies that touch on this intersection, a few discuss HIV exposure and access to treatment for MSM residing in rural areas, such as the research done by Hubach et al (2015; 2017). While looking at HIV exposure and treatment access for MSM in rural settings is an important topic, a large demographic of the LGBTQ2S+ community is not represented in that research. Alas, in Hubach et al's (2015; 2017) research, two main themes were the most prominent:

the effects of sexual stigma were multiplied in rural areas that had a heavy religious presence; and rural areas were lacking in appropriate resources for MSM to draw from, such as availability of PrEP (pre-exposure prophylaxis, a drug that has been proven to reduce HIV incidences) and the medical expertise to prescribe it. These findings are also echoed in Scheim and Travers’ (2017) research on trans MSM’s sexual health overall, where it was found that access to affirming sexual health resources was deficient even in a city as resource-rich and populated as Toronto.

Given that rural settings tend to be more widespread geographically and less central, another concern that Hubach et al’s (2015; 2017) participants voiced was that accessing appropriate sexual health resources was challenging given the geographic difficulties; this is a finding that Higginson (2012) also saw with rural-residing youth who were unable to access sexual health services due to transportation limitations. One particular phenomenon that was expressed by Hubach et al’s (2015) participants that was also a concern in Higginson’s (2012) research was the disclosure of sexual identity, HIV status, and/or the need for sexual health resources in a rural setting where anonymity could be compromised due to the smallness of the community. This is a valid concern, especially since LGBTQ2S+ individuals residing in rural areas live at intersections that ‘other’ them if they are not living within narrowly-defined culturally constructed norms (Hubach et al, 2015).

Confidentiality and anonymity within a rural context are elements that factor into an LGBTQ2S+ individual’s decision to access services within their community. In Gottschalk’s (2007) research, participants talked about how they were fearful that their service providers would out them and break confidentiality if the participants were to bring up their sexuality. Participants also discussed how even borrowing an LGBTQ2S+ book from the library was not worth risking getting outed for (Gottschalk, 2007). When Gottschalk (2007) asked their participants what sorts of desired services they would want to see in their rural community, an LGBTQ2S+-friendly medical doctor was the second-most wanted, following an LGBTQ2S+-friendly counsellor. Similarly, in Kazyak's (2011) research on LGBTQ2S+ cultural narratives within rural settings, they found that 'everyone knows everyone' in a rural community, thus resulting in limited anonymity and confidentiality. However, Kazyak's (2011) research emphasizes the resiliency and strength that comes from the interconnectedness, as the author describes it, that is found in a rural area, which is not an aspect of rural LGBTQ2S+ living that is often focused on (Kazyak, 2011).

### *b. Heteronormativity*

The pervasiveness of heteronormativity within health and sexual healthcare systems and institutions continues to set up barriers to effective and appropriate services to LGBTQ2S+ communities in Canada (Mulé et al, 2009). According to Carrotte et al (2016), heteronormativity is the assumption of heterosexuality and a cisgender identity that is placed on individuals, which is often shaped by social biases, stereotyping, and privilege. Experiences of heteronormativity are seen as being a distinctly separate entity from experiences of homophobia, whereby heteronormativity in healthcare is characterized as the erasure of gender and sexually diverse people as opposed to hatred towards them (Carrotte et al, 2016). Carrotte et al's (2016) research found that the heteronormativity in healthcare (and in turn barriers to healthcare) was experienced by LGBTQ2S+ individuals when identities were invalidated, when they did not receive appropriate sexual healthcare, and when they encountered stigmatizing language and assumptions about their experiences. In contrast, Albuquerque et al's (2016) systemic review of health service access for LGBTQ2S+ populations found that service provider homophobia was one of the biggest deterrents to accessing healthcare. It is, therefore, safe to conclude that heteronormativity and homophobia are both responsible for making healthcare access for LGBTQ2S+ individuals a particularly challenging experience.

Mulé et al (2009) explain how heteronormativity manifests itself in social policy and integrates into the very structures that shape life, making heterosexuality the 'default' and thus anything outside the norm is seen as deviant. While heteronormativity is not always specifically named in the literature but is instead usually insinuated, it is seen as one of the leading barriers to healthcare services for LGBTQ2S+ populations.

Experiences of heteronormativity while attempting to access healthcare services deter LGBTQ2S+ people from these services, which only adds to the perpetuation of the stigma and shame around queer and trans sexual health (Carrotte et al, 2016; Mulé et al, 2009; Keuroghlain, Ard, & Makadon, 2017). Campbell (2013) explains that when LGBTQ2S+ people attempt to access sexual health services, heteronormative assumptions often prevent them from receiving appropriate care. For example, one study showed that one in five lesbian and bisexual women were given incorrect information about their sexual health (Hunt & Fish, 2008). In Carrotte et al's (2016) research, LGBTQ2S+ participants described experiences of healthcare providers dismissing their sexual identities, using stigmatizing language, and making hypersexualized assumptions about queer patients' sexual experiences. Moreover, in Scheim and Travers' (2017) research, transgender MSM explained how they have often foregone accessing sexual healthcare altogether because of their experiences of cisnormativity, heteronormativity's sibling. When in a healthcare setting, especially when discussing a topic as sensitive as sexual health, LGBTQ2S+ individuals who face heteronormativity and cisnormativity are often reluctant to push back against these assumptions as it is not easy to both educate one's healthcare provider while validating one's experiences simultaneously (Campbell, 2013; Carrotte et al, 2016; Scheim and Travers, 2017). Unfortunately for LGBTQ2S+ populations, sexual health services are not immune to the heteronormative and cisnormative assumptions that come with simply existing in society, and it is indeed a shameful thing that happens in so-called 'LGBTQ2S+ friendly' countries like Canada, the UK, and the US.

### *c. Lack of Healthcare Practitioner Education & Knowledge*

People who identify as LGBTQ2S+ have a plethora of sexual health needs that differ from the needs of people who identify as heterosexual (Campbell, 2013). This is especially the case with regards to STI and HIV education, prevention, and support (Campbell, 2013). While this is not concerning in and of itself, what is concerning is the fact that the healthcare sector is not proficient, culturally competent, or well-informed on LGBTQ2S+ health issues, especially when it comes to sexual health.

In Hubach et al's (2017) research, MSM expressed how they were concerned about being seen by a healthcare provider who would not be affirming of their sexual orientation and would not know enough about HIV prevention drugs such as PrEP. Similarly, one of the difficulties expressed by trans MSM in Scheim and Travers' (2017) research was the lack of knowledge of trans issues among testing providers, even if the provider was touted as being trans-friendly. For example, one of the participants discussed how, even though the healthcare service they went to was trans-friendly on their forms, they did not have the right equipment or tools in their offices to perform the appropriate procedures on trans patients (Scheim & Travers, 2017).

When it comes to gender-nonconforming people, the problem of healthcare practitioner incompetence and lack of LGBTQ2S+ knowledge is multiplied, especially in a system that is so adamant on upholding the gender binary (Scheim & Travers, 2017). Non-binary identities are still not paid enough attention to when it comes to sexual health, and that leaves a lot of vulnerable individuals falling through the cracks and either receiving terrible healthcare or not accessing it at all (Carrotte et al, 2016).

The central focus of Keuroghlian, Ard, and Makadon's (2017) paper is how to rectify the lack of knowledge and skills needed for LGBTQ2S+ patients to receive affirmative, high quality sexual healthcare. The authors advocate for better LGBTQ2S+ sexual health education for both current healthcare practitioners as well as trainees through not only capacity building and training, but also through the integration of LGBTQ2S+ sexual health knowledge into existing clinical curriculum, advising that this serious issue simply cannot be solved within a three-hour workshop (Keuroghlian, Ard,

& Makadon, 2017). The literature is not lacking on the need for this type of healthcare reform, as was seen in a Swedish study where only 10% of nursing students demonstrated a 'passing level' of LGBTQ2S+ care knowledge, which could be attributed to the lack of coverage of LGBTQ2S+ health issues in nursing education (Lim, Brown Jr, & Sung Min, 2014).

### *d. LGBTQ2S+ Populations in Policy Discourse*

LGBTQ2S+ populations are often discussed homogenously in policy discourse, if at all, while being distinctly separated from other marginalized communities and oftentimes not even recognized as a vulnerable population (Mulé et al, 2009). It is hypothesized and explained by Mulé (2005) that suppressing homosexuality feeds social policy, which only goes to embolden a particular type of sexuality -straightness- through policy practice. It was pointed out in Mulé & Smith's (2014) research that, in the policy documents and research reports that they analyzed, there was a resolute lack of mention of LGBTQ2S+ health in the overwhelming majority of the documents. To make matters even more abysmal, Jackson, Daley, Moore, Mulé, Ross, and Travers (2006) explain how health disparities in sub-populations like LGBTQ2S+ populations are measured as they deviate away from the dominant population, which is seen as the centre (as in, white, middle-to-upper class, able-bodied, cisgender, heterosexual males). This is an incredibly problematic approach as it muddles the privileges assigned to the dominant groups and obscures the power relations that are both producing and maintaining inequalities as they relate to policy creation (Jackson et al, 2006). In a way, this method of measuring something so crucial to one's life, health, sends a message that LGBTQ2S+ populations will forever be living on or outside the margins, and will always be seen as 'the other', rather than people who deserve to be treated with dignity and respect.

A critical finding from Mulé et al's (2009) research on LGBTQ2S+ inclusive policies is that, despite LGBTQ2S+ populations having defined for themselves what their health needs and concerns are, Health Canada's approach to health analysis is based on standardized individual experiences in the healthcare system. This means that it does not pay attention to the rich qualitative data that is coming out of the research. As such, Health Canada fails to analyze the impacts of social relations, structures, and forces on health. This is perfectly demonstrated in Carrotte et al's (2016) research where inaccurate data was collected because their survey did not adequately capture LGBTQ2S+ populations' experiences of sexual health; this also lead to the participants feeling invalidated in their experiences and identities as a whole. The literature then clearly demonstrates that Canadian health policies are not only exclusionary of LGBTQ2S+ populations, but that this exclusion is not being taken seriously enough to tend to the health and wellbeing of queer and trans populations.

## 2. Filling the Knowledge Gaps

It is worth mentioning that the literature is almost void of conversations about LGBTQ2S+ populations residing in rural areas, other than Hubach's (2015; 2017) research. This does a huge disservice to LGBTQ2S+ populations who are marginalized not only because of their sexual orientation and/or gender, but also because of all the negative side effects that come from living in rural settings that may not be the safest for LGBTQ2S+ populations. Moreover, while the literature has done a fairly adequate job of describing LGBTQ2S+ populations' access to sexual health and general healthcare, the majority of the research has been conducted, as previously mentioned, in biomedical, nursing, and health science research (Mulé et al, 2009; Lim, Brown Jr, and Sung Min, 2014). My MSW research will attend to this gap by looking at access to sexual healthcare from the point of view of service providers and community members who have experienced barriers to accessing sexual healthcare. Consequently, I will go beyond the illness or disease-based approach rather and instead, attend to a social context and social determinants of health approach. Echoing Mulé, I plan to seek out potential prevention strategies as well as an opportunity to structurally analyze the barriers and facilitators for sexual health.

### *a. Experiences of Trans and Non-Binary Populations*

An issue I have repeatedly found in the literature is that even though the acronym LGBTQ2S+ includes transgender (trans) populations, this population often gets swept up under the larger LGBTQ2S+ umbrella without enough recognition that trans communities face a different form of-often worse- discrimination when accessing healthcare due to transantagonism. In fact, some research is outright exclusionary of trans identities, such Hubach et al's (2017) study that discusses sexual healthcare for MSM and PrEP access in rural settings but specifically states that being 'born male' is a requirement to qualify, without any explanation as to why trans MSM were excluded. Moreover, there are a small number of studies that focus primarily and solely on trans and non-binary individuals' experiences with healthcare, though they are few and far between, especially the ones that focus on sexual health. Scheim and Travers' (2017) is one of the very few - if not only- Canadian research study that discusses trans MSM's experiences accessing sexual health, and even then, there is an absence of non-binary and gender non-conforming voices.

Another highly problematic pattern the literature has demonstrated is targeting specific sexual health resources for cisgender gay men and excluding trans and gender non-conforming individuals altogether from the research. For example, Muscolino's (2016) community-based HIV prevention campaign was almost strictly targeted at gay MSM and did not mention trans or non-binary individuals, despite the fact that they could benefit from the campaign. This seemingly intentional exclusion of trans and non-binary populations from sexual health research can have detrimental consequences on individuals' health and wellbeing and communicates the message that these populations are not worthy of being included in important research. I plan on addressing this gap in this research by including trans and non-binary individuals' stories and experiences of accessing healthcare and focusing on how transantagonism has a detrimental effect on their lives.

### *b. Focusing on Resiliency*

What is lacking in the literature is discussion of LGBTQ2S+ resiliency and perseverance when accessing sexual healthcare services despite the odds being stacked against them. While LGBTQ2+ populations do face many barriers to sexual healthcare, they do not all give up and forego healthcare access altogether; some find creative ways of navigating tricky and oppressive systems, and those are conversations I aim to uncover in my research while holding privilege in mind. While I think the recommendations and objectives that the literature lays out can be of use in certain contexts, I believe most of them put the focus on shifting already-existing structures and systems that have proven to be challenging to change. Instead of suggesting recommendations for better sexual healthcare access to LGBTQ2S+ populations living in rural settings, I aim to instead shed light on how some communities have already found ways of resisting and pushing back against these inequitable systems, and so I believe we already have a starting point that deserves attention.

### *c. Intentions of this Research*

As my research includes talking to service providers and community members about barriers to sexual health services for the LGBTQ2S+ population in a rural city, it will touch on the many intersections, nuances, and complexities that are involved, which is what the literature is lacking. As such, my research will not be guided by what is already known, but also by community members, which is another element that is not often found in the literature when it comes to discussing a topic so heavily medicalized such as sexual health. Moreover, my research will target a niche population of LGBTQ2S+ people, which is those who reside in rural areas and face not additive but multiplicative disadvantages because of the many social identities that they inhabit (Hsieh & Ruther, 2017).

# Chapter 3: Methodology

## 1. Theoretical Framework

Connecting theory to practice has never been my strong suit; theories usually made sense on paper but escaped me when it came down to being used in placements in my undergraduate degree. It was strange seeing colleagues have such an in-depth understanding of how theories applied to social work practice that I began thinking that I just do not care enough for that element of social work. However, I have slowly learned over time that I do indeed care for theory and its application in the field, instead, I have just been taking my own knowledge for granted this whole time. Certain theories have gotten so embedded in my worldview that untangling where my own thoughts start and where the theory ends feels like an insurmountable task. For example, certain principles of community-based research (CBR), as well as critical theory, have been subconsciously weaving into my own values and ethics for a number of years now, influenced by community work, radical politics, and a thirst to pick apart social systems and structures. After much thought on what theories and frameworks my epistemology naturally aligns with, I have designed my thesis to include certain principles of CBR that are attainable in a short period of time, and the deconstruction of the systems that I shall be looking at will be done using critical theory. I will be going into detail about each of the frameworks I have mentioned and speak as to why I have chosen them to guide me through my research.

### *a. Critical Social Science*

Critical theory plays a vital role in my research not only because I am a critical thinker through and through, but because it lays down the foundation to understanding how systems are covertly oppressive and unjust (Freeman & Vasconcelos, 2010). Moreover, critical theory helps us discover where power lies within systems and who benefits from how society is currently operating (Capper, 1998). Neuman (1998) states that critical research's purpose is to change the world; this is done through uncovering oppressive societal structures to aid people in changing those conditions and building a better society for everyone. According to Freeman and Vasconcelos (2010), critical theory can be participatory in nature because the knowledge of how social systems have gotten entangled around a specific context or practice is not known, thus it is crucial to engage with stakeholders in order to understand how oppression exists and operates. Additionally, it is a relief for me to know that critical theory is meant to be incorporated into one's practice, as it is seen as being "intrinsically embodied in praxis in the way humans act out their theoretical versions of the world" (Freeman & Vasconcelos, 2010, p.9). I appreciate and agree with what Neuman (1997) points out about critical theory, which is that using a critical approach means that we are aware of the fact that our initial observations are only partial truths, since our own knowledge about any given system is usually limited and requires further investigation. This idea partners well with a CBR approach where it forces researchers to consult with community members and leaders in order to seek out the knowledge that is not available to people unless they interact with those systems in some capacity.

### i. *How Critical Social Science Applies to my Research*

I have always been drawn to critical social science, as I have briefly touched on earlier, but it is particularly appealing and useful to my research because I need to discover the real happenings of the community when it comes to accessing sexual health services. While I am using the knowledge of service providers and community leaders who are familiar with these services and their city's climate, critical theory also urges me to keep in mind who has power within these systems and who does not. I think it is important to give an example of how critical theory has helped me in my research. The Collaborative who I am working with is a group of people who are working towards improving the lives of LGBTQ2S+ individuals in their area, and they are the ones who are providing me with the data for my research. While I am always asking myself questions regarding whiteness and race, I was not aware of how to go about addressing those issues in a seemingly all-white space; I am also cognizant of the power differences between both myself and the members and between the members themselves. It is equally important to pay attention to the power that members have over deciding what gets focused on and what is ignored. As such, reminding myself that I am critical in my inquiries has been encouraging me to ask uncomfortable questions and be okay with it, as opposed to remaining silent about issues that I think are not being addressed. I went about my research using the same critical lens that helped me discover an unquestioned problem that adds to the data -or, more accurately, lack of data- regarding sexual health services.

### *b. Community-Based Research (CBR)*

CBR has been described by Israel, Schulz, Parker & Becker (1998) as filling in the gaps that positivist science has left behind through taking up both a critical and constructivist lens. CBR would be able to answer some important questions, given CBR cares about subjective knowledge, as opposed to objective knowledge that is separate from its knower (Israel et al., 1998). CBR has been appealing to me since my first year of my undergraduate degree, where I started introducing CBR principles into my own personal framework and worldview; it has been difficult thinking of research being conducted any other way since then. CBR is known to be a collaborative way of conducting research *with* community partners rather than on them, where the strengths and resources of the community are recognized and built upon (Christopher, Watts, McCormick, & Young, 2007; Israel et al., 1998). Building trust between researchers and community partners is a necessary step in any CBR endeavor, since very little can be done without it (Christopher et al. 2007). My favourite quote that encompasses what CBR means to me is "nothing about us without us", coined by HIV/AIDS communities in the 1980s (Graham, 2014). While CBR is less of a theory than an approach to doing research, the approach has strong links to critical theory and is a framework that is used to guide research practices (Saara Greene, personal communication, 2017). CBR is a way of understanding how research ought to proceed; it is the study of methods, including the explanation and justification, but not the methods themselves (Carter & Little, 2007).

### i. *How CBR Applies to my Research*

Knowing CBR focuses on community collaborations and not just doing research for the sake of doing research, it was vital for me to make sure that my thesis would not just be a stand-alone project: that it would be used towards some kind of social reform. I also knew I would be able to do none of that alone, and that I would need community partners who were willing to be a part of the project. Luckily, I found a group -the Collaborative- that was interested in contributing to the project. One of the most important elements of CBR that I hope I am doing justice to is being able to take guidance from the community partners regarding the key components of the project. While I would have loved to involve them every step of the way, the nature of my thesis unfortunately did not allow that. Regardless, I wanted to give the community partners as much agency as I could -within the restrictions of the ethics board- for them to shape the project in the ways that they saw fit.

### ii. *CBR Principle of Participation & Meaningful Collaboration*

While having conversation with a colleague who is well-versed in CBR, they spoke about how not only is the concept of community fluid, but CBR also exists on a similarly fluid continuum: it goes from having minimal contact with community members to having collaborative partnerships with communities, with multiple steps in between (Allyson Ion, personal communication, 2018). As Ball (2014) explains, CBR researchers' guiding principles ought to include community participation and mutual capacity building. However, community participation is a vague concept that itself lies on a spectrum, which becomes apparent when we ask the question "how *much* is *enough* when it comes to participation?" The term 'meaningful collaboration' is being used intentionally because in order for the collaboration with community and with the participants to be valid, it needs to be meaningful *for them*, not just for the researchers (Strand, Marullo, Cutforth, Stoecker, and Donohue, 2003). The fact that CBR projects are collaborative by nature makes them effective at facilitating learning for everyone involved, especially the researchers (Strand et al, 2003); I believe this to be a humbling experience since most researchers usually consult with academia for knowledge acquisition, yet CBR situates that knowledge on the ground with the people who are living the experiences.

The notion of participation is another concept that exists on a spectrum. First and foremost, according to Travers et al (2008) and Pinto, McKay, & Escobar (2008), having community members even want to participate in a CBR project requires a cocktail of ingredients that need to be present, such as trust, valuing lived experience, and being understanding of community needs. However, it does not stop there: each of those concepts is (yet again) a spectrum, and there are certainly more parts that need to be present in order for CBR projects to succeed and for the communities they are involved in to thrive. An element to be mindful of when negotiating participation is that of covert power relations between the participants and the researchers. Greene (2013) describes a particular ethical tension that came up in her research where she was concerned that the participants were unable to refuse participation due to underlying power relations between the two parties; gratitude for involvement in the research project was a large contributing factor as well. This is an easy tension to ignore or not pay attention to because of its subtleness, yet it is vital to negotiate and reflect on how to mitigate those power relations; deflecting gratitude towards the community instead of the researcher could be a useful tactic, as Greene (2013) found. On the other side of the spectrum, if participants choose not to participate, it is not on the researchers to judge how committed they are to community work, since that work does not just look like being involved in academic research but has other forms as well; only people themselves can determine what their capacity for involvement is.

### iii. *CBR Principle of Community Consultations*

This principle nestles in naturally under the umbrella of participation and meaningful collaboration but deserves to be discussed on its own as well. Traditionally in CBR projects, community advisory committees are set up and consulted with in order to ensure the community has a strong voice and influence throughout the project (Maiter, Joseph, Shan, and Saeid, 2013); depending on their specific roles, these committees or groups could take on different names, such as community engagement team instead (Travers et al, 2013). The main reason I decided to conduct community consultations early on in my project was because I wanted to clarify right from the beginning that this research was not mine, it was the community’s, meaning that their say would dictate the research’s direction. In complete transparency, I highly doubt this research would have actually materialized at all if it was not for the community consultations that were held, because they were an incredibly powerful force in steering both the small and large research questions in the right direction. The consultations were often a mix of formal and informal meetings, conducted at coffee shops, people's homes, offices, and community centres.

### iv. *CBR Principle of Building & Maintaining Trust*

Building and maintaining trust is one CBR principle that can, in my opinion, make or break the research project. Particularly for vulnerable and marginalized populations such as the LGBTQ2S+ community, building trust is imperative since members can be wary of outsiders due to a history of exploitative research practices (Van der Meulen, 2001). According to Christopher et al (2007), academic researchers coming into communities being seen as 'experts' can hinder the trust-building process. Alternatively, academic researchers ought to be present in the community, acknowledge its members' expertise, and honour their words and promises in order to begin the trust-building process (Christopher et al, 2007). In my research project, building and maintaining trust was vital in order to be able to move forward; if the participants did not trust me, then they would have had no reason to show up for meetings or share their thoughts with me. Given I live a considerable distance away from the rural community my research was in, I put in a substantial amount of effort to ensure I was present in the community, participating in meetings, and attending events to the best of my ability; this was my way of building trust with the participants and the community at large.

It is also important for me to acknowledge that the fact that I have some insider knowledge of this community -given I am a member of the LGBTQ2S+ community- and this has been helpful in expediting the trust-building process; Van der Meulen (2001) explains this in their research where sex workers only participated in research projects that had current or previous sex workers on their team. Moreover, I believe being transparent right from the beginning helped establish trust between myself and the participants since I clearly articulated my intentions within this research, what data collection could look like, how ethics was approved, and how the data dissemination process could occur; I also maintained this trust by continuing to have open communication with them about the focus groups and the data analysis process.

### v. *CBR Principle of Reciprocity*

Reciprocity, according to Maiter, Simich, Jacobson, and Wise (2008), is explained as "an ongoing process of exchange with the aim of establishing and maintaining equality between parties" (p.305). The authors go on to discuss how reciprocal dialogue, where researchers and participants engage in conversation as equals, could help iron out ethical complications in research (Maiter et al, 2008). Maiter et al (2008) center two ideas in the concept of reciprocity: equality, which addresses power, and exchange, where all parties involved benefit. While I find some elements of this definition problematic, it is still important to include how academics define reciprocity, as opposed to just offering my personal take on it. A definition that I agree with and prefer is that of Greene's (2013), where reciprocity is described as "an open and conscious negotiation of the power structures reproduced during the give and take interactions of the people involved in both sides of the research relationship" (p. 148).

While the concept of reciprocity at face value seems straightforward, it is worth troubling it in order to get a better understanding of how it is operationalized in research. Some questions I have regarding reciprocity include: who gets to decide if someone has reciprocated enough; is there a quantifier involved, or does the other party get to dictate this; and is it frowned upon to not explicitly reciprocate. I ask these questions because in my research, it is almost guaranteed that I will be pulling in more work on my end to make the research happen, to coordinate consultations, and to obtain results out of the focus groups, and that is not something I am bitter about; it is simply my role. When I presented the participants with opportunities to participate and guide the research, I did not want them to do so because they felt indebted to me for attempting to get data that will -hopefully- help their community, but I wanted them to participate because they genuinely wanted to.

Thinking about and experiencing power differences is an unavoidable topic in any situation where academia, funding, and community are involved. I would argue against looking at power difference as being inherently negative, but instead as something to acknowledge and then be mindful of its effects and consequences thereafter. I do not think it is realistic or entirely possible to abolish power differences, but I do believe in recognizing how they shape relationships and then working towards mitigating their negative consequences; it is why I appreciate Greene's (2013) use of the expression "conscious negotiation of … power structures" (p.148) since that does the fluidity of power in relationships more justice.

While I strived towards egalitarianism in my research, the project was still technically considered 'my' project in academia's eyes, and my graduation is based on it. In my opinion, being mindful of the power difference was important because it grounded me in the CBR principles I was working from by reminding me that the power *should not* belong to me, even if it did.

### vi. *Ownership and Use of Data in CBR*

The ownership and the use of research data in CBR projects lies on a spectrum, ranging from more 'traditional' forms of research where researchers retain control and ownership of the data, to more progressive forms of research where the community is seen as an owner of the data rather than just a partner (Travers et al, 2013). The term OCAP, which stands for ownership, control, access, and possession of research material, was coined by and for First Nations communities in Canada to as an expression of self-determination in research; it applies to other Indigenous communities as well (Schnarch, 2004). While the conditions of OCAP do not apply to non-Indigenous research, some of its principles can still be used effectively in CBR projects.

Community ownership was one of the main principles in Travers et al's (2013) research and was something that was of high importance to the community as well as to the researchers. In my research, I have adopted a similar position, openly stating to the Collaborative, research Partner, and to the participants that the data and the results of the research do not belong to me, but to them instead, explaining that that is an integral part of why this project is CBR-based. Furthermore, what they choose to do with the research is entirely up to them; they do not need my permission.

## 2. Research Methods

### *a. Partnership Development Process*

#### i. *Connecting with the Community Partner*

Given that developing community partnerships is one of the main cornerstones of CBR (Israel, Schulz, Parker, & Becker, 1998), this component was naturally a large focus in my research. During our first meeting with the AIDS Network, we discussed the parameters of how my research would fit in and what everyone was bringing forth into the project. We discussed how the partnership would be mutually beneficial and established future meetings to discuss next steps. During this first meeting, I met the individual who would be my point-of-contact to the AIDS Network; this individual would later be the person who would connect me to the research participants and would become a participant themselves. After several successful meetings with the point-of-contact person, they decided it would be a good idea for me to sit in on a Collaborative that they attend and meet the people around the table. I would attend the following meeting after their suggestion.

#### ii. *Connecting with the Collaborative*

The Collaborative is comprised of a mix of members of the LGBTQ2S+ community and their allies. A large number of the Collaborative members have the dual role of service provider and community member, given the smallness of the city. The Collaborative meets once a month and discusses LGBTQ2S+ issues in their rural community; it is entirely volunteer-based. The Collaborative has extensive ties in the community and has about ten to fifteen members around the table each month.

During my first time meeting the Collaborative in December of 2017, I introduced myself and what I was hoping to accomplish through spending time with them. I expressed the fact that I was aiming to work from a CBR perspective and was hoping to take the community's direction on what the research ought to look like. They welcomed me and expressed interest in having me at their table. I began attending their monthly meetings and getting to know the members better, while also participating in the discussions. Aside from attending the Collaborative meetings, I also had separate consultations with members who were particularly keen on helping me with the research project. It is important to mention that the relationships that I developed with the Collaborative over a number of months were crucial for this research. Overall, the ongoing consultations both with the Collaborative as a whole as well as with its individual members made it possible to recruit them into the research.

### *b. Recruitment*

As a result of my ongoing consultations with the Collaborative in the development stages of the research, a relationship with the community had already been established. As such, once my ethics application was approved, I approached the Collaborative and informed them that I could officially begin the recruitment process. I once again explained my research and my interest in holding focus groups, and then passed around a sign-up sheet asking those who would be interested to participate to write their name and contact information; I also asked them if they would prefer to meet before or after the usual Collaborative meeting. After the sign-up sheet had gone around the table, I told the Collaborative that I would send the Letter of Consent and Information (see Appendix B) to those who provided me with their emails so that they could read it over and ask questions before the focus groups took place.

### *c. Participants*

Two focus groups were conducted where a total of twelve participants discussed sexual health services for LGBTQ2S+ individuals in a rural Ontario city. Eight of the participants identify as part of the LGBTQ2S+ community. The focus groups were comprised of both service providers and community members. In order to maintain the anonymity of the participants, the only distinction I use in my research is that between service provider and community member. A number of the participants exist in both of those roles simultaneously where their identities overlap, thus I shall be using my discretion to use the best identifier that would deliver the intended message but also conceal their identity. This is being done as per the suggestion and request of the participants themselves.

### *d. Data Collection*

#### i. *Participant Observation*

In order to understand the inner workings of the Collaborative, I decided to utilize the qualitative method of participant observation for my research. Historically, participant observation has been used to understand the lived experiences of cultural groups around the world; it is also a method that has been used to complement CBR projects (Hammer, Fletcher, & Hibbert, 2017). Participant observation, according to Dobrin and Schwartz (2016), puts an emphasis on embracing one's role as a researcher as opposed to avoiding it and disappearing into the background. The participant observation method contains two components: the participation, and the observation. The former asks the researcher to engage with the norms and way of life of the group they are studying, while the latter asks the researcher to take notice of the dynamics and cultural phenomena occurring; the starting point of analysis is always the participants' experiences, viewpoints, and ideas (Zahle, 2017). Lastly, it is important to note that the researcher's personal investment in the social relationships being formed in the community is seen as a significant step in understanding the community's point of view (Dobrin & Schwartz, 2016).

In my research, the utilization of the participant observation method began in the consultation phase, since I was in the process of integrating myself into the Collaborative for an extended period of time. This particular method is said to create a fringe position of concurrently being on the outside as well as on the inside (Hammer, Fletcher, & Hibbert, 2017). I attended a total of 6 monthly meetings and after each meeting, I wrote down my reflections of how the meeting went; I also did this process for the handful of consultations I had with individual members of the Collaborative. These reflections went on to become my field notes.

### ii. *Focus Groups*

According to Kitzinger (1995), the process of discussing a particular topic in a group setting could aid the participants in feeling more comfortable sharing their viewpoints, as opposed to a one-on-one interview. The interest in focus groups was expressed during the consultation process at the beginning, and the scheduling of the focus groups was easy since the Collaborative already met at a particular day of each month. Two focus groups were conducted in order to account for some individual circumstances around scheduling. In both focus groups, the participants already knew each other and worked closely together which helped facilitate the focus group conversations even farther, since they felt comfortable expressing their views in a safe space with their peers.

Food practices are rooted in our everyday life and are significant in building and maintaining social relationships (Neely, Walton, & Stephens, 2015), which was a critical component of my CBR approach to data collection. Being mindful of the importance of food, I made sure to check in with the group about food preferences, sensitivities, and restrictions so I could provide food at the focus groups that was appropriate. Both focus groups partook in the sharing of food throughout the interviewing process. Focus groups were taped and transcribed verbatim.

### *e. Data Analysis*

#### i. *Field Notes*

Writing field notes is a research technique that is often used in ethnographic research (Wolfinger, 2002). The researcher engages in this process by jotting down observations of their experiences while conducting research. Because of the fact that the researcher walks into any given project with their own unique social location, preconceived notions, and judgements, what ultimately gets written down into the field notes is coming from a particular lens (Wolfinger, 2002). Ryan and Bernard (2003) explain this filtering-process as being potentially problematic if it is not something that the researcher is cognizant and reflective of.

While engaging in participant observation through both the monthly Collaborative meetings and the consultations with the members, I took down field notes of what I had observed, including my own thoughts and feelings about what was said. Field notes were thus separated into two: one that included what had happened in the meetings, such as what had been discussed; and one that had my own thoughts, feelings, and reflections, such as my frustration at the rain that made me late to the meeting. The field notes were taken by pen and later typed into a word document.

The field notes that were taken shaped the focus group data in two distinct ways. Firstly, they acted as a guide to the creation of the focus group questions (see Appendix C), and thus influenced what the focus group conversations looked like. Secondly, they helped guide me in the creation of the themes since they were influencing the way I was looking at the focus group data. It is important to point out that the themes that have come from the focus group data have been influenced by the field notes that were taken throughout the consultation process, whether that influence was subconscious or conscious; my own worldview has undoubtedly been a part of the data collection process due to the nature of this qualitative research.

### ii. *Thematic Analysis*

Thematic analysis is a technique that is widely used in qualitative research (Nowell, Norris, White, & Moules, 2017), and it is the technique that I have used to analyze the focus group data. It involves "identifying, analyzing, organizing, describing, and reporting themes found within a data set" (Nowell et al, 2017, p. 2). The themes were created through the use of inductive, or interpretive, analysis, which is described as a method of coding the data without the use of a pre-existing theoretical framework; this type of thematic analysis is considered to be data-driven, as opposed to being theory-driven (Nowell et al, 2017). Simply put, it means becoming familiar with the data through reading it over a few times and then making observations in the margins, which later turn into codes (Mason, 2002; Ryan & Bernard, 2003). The codes were organized into themes through paying attention to repetitions, similarities and differences, as well as what was missing from the data (Ryan & Bernard, 2003). The computer program Quirkos was used in order to sweep the data and create the codes through assigning different sized shapes and colours to the codes. I understand this to be akin to the 'cutting and sorting' method that Ryan and Bernard (2003) explain as physically placing quotes on top of each other to create piles of similar quotes, which would then turn into themes.

While transcribing the data, I took note of the identifiable information that participants were sharing and took steps to ensure the information was masked, changed, and blurred to hide anything that could be identifiable. Some of the quotes that I have used have also been modified to account for identifiable language or style of speaking.

### *f. Ethics*

This research has been given ethics approval from the McMaster Research Ethics Board (MREB). The anonymity of the participants was one of the major ethical considerations that was brought back from the MREB. The concern was, given the smallness of the rural community I was engaging with, that the participants would be identifiable. Initially, I had intended on using participants' job titles (if they were relevant) in order to add weight to their words. However, that was seen as identifying information. As such, I removed the need to add job titles and instead decided to use vague descriptors to conceal their identity, such as service provider and/or community member; I also opted to use gender-neutral pronouns (them/they) in order to further conceal the participants' identities.

Another ethical concern brought forth by the MREB was that of recruitment. I was advised to be cautious of any coercion that might occur between participants and community members while going through the process of snowball recruitment. In response to this, I kept the recruitment confined to the members of the Collaborative; some members of the Collaborative took it upon themselves to reach out to their coworkers -at their discretion- who they thought might be interested and connected them with myself for further information.

Before the focus groups took place, all the participants signed and kept a Letter of Information and Consent (see Appendix B) which outlined confidentiality and the steps that I would take to ensure their anonymity. However, due to the nature of focus groups, the participants were aware of the fact that I, as the researcher, cannot control what others decide to share outside of the focus group, and as such to be mindful of what they share.

# Chapter 4: Findings, Analysis, & Discussion

Although the themes and subthemes discussed in this chapter are presented as distinct issues and concerns, they are all interconnected and are incomplete without one another's contexts, explanations, and details. The main themes emerging from the focus groups and my field notes include: experiences of heteronormativity, queerphobia and transphobia; service access barriers; and community responses and strategies to address those barriers. While the findings are often separate from their analysis and discussion, I have combined all three in this chapter in a way where I present the findings, offer my analysis, and then link that to the literature.

## 1. Heteronormativity, Queerphobia, & Transphobia

The experiences of the participants and the people they live and work with are grounded in a broader social context of heteronormativity, queerphobia, and transphobia, making it a key theme in this research both when it is experienced explicitly, as well as when it is the underlying context in the background. Stories of heteronormativity, queerphobia, and transphobia will be discussed in this theme both as a stand-alone issue as well as within healthcare settings, specifically while accessing sexual health services. Stories of how inadequately informed service providers perpetuate heteronormativity, queerphobia, and transphobia will also be included and discussed.

### a. *Stories of Heteronormativity, Queerphobia, and Transphobia*

In order to be able to talk about the range of barriers to sexual healthcare that LGBTQ2S+ communities residing in rural areas experience, it is necessary to first demonstrate the social context in which people in these communities live out their lives more broadly. Heteronormativity, sometimes described as heterosexism by the participants, was seen to be such a 'normal' experience that it was not often explicitly named but assumed to be a given; one participant nonchalantly discussed how the assumed heterosexism they were seeing in their workplace was expected when they stated:

> *"So there' s obviously the assumed heterosexism, but if people are out, it's like more of even trying to stifle the behaviour than trying to provide positive information."*

The participants discussed how they had experienced and witnessed heteronormativity, queerphobia, and transphobia in many elements of their lives. One participant explained:

> *"I also find there's still a lot of stigma around queerness … as being like, dirty and problematic, and I remember even when the first Prides were being organized, there was a lot of concern amongst the Pride organizers … about being really careful to have a family-friendly event that didn't emphasize the pieces around sex and sexuality."*

This participant's experience demonstrates that living in a heteronormative society where queerness is viewed as deviant results in having to be careful about how one's sexual identity is demonstrated publicly. When queerness is associated with being 'dirty' or 'problematic', then the safety of an LGBTQ2S+ individual is up for question, making society a dangerous place for them to navigate.

One participant connected the societal stigma associated with identifying as LGBTQ2S+ to experiences of attempting to access to sexual health services:

> "*There's so little comfort in general with sex and sexuality … anything related to sexual health services in the first place has been a challenge*".

Echoing Hubach et al (2017), healthcare services are already a sensitive service to access due to the societal stigma associated with sex, and so adding an extra layer of queerness and/or transness makes it even more challenging. One participant explained:

> *"… when you have that much marginalization of sexual health in general, you're then going to have triple or quadruple the level of marginalization for queer sexuality."*

Another participant talked about how subtle heteronormative messages could be:

> *"I think there's a lot of discussion around heteronormative sex, so when you walk into your doctor's office, there's a bowl of condoms, but are there like, dental dams, or female condoms."*

The participant explained how heteronormative behaviour is so embedded in our society that it dictates how we go about our lives, including how we access necessary services such as healthcare.

Heteronormativity, queerphobia, and transphobia affect people in very real and life-altering ways, often also influencing how LGBTQ2S+ people perceive themselves and others in their communities; being exposed to queerphobic and transantagonistic behaviours can often lead to internalized queerphobia and/or transphobia (Williamson, 2000). Moreover, when the starting point is an already-existing discomfort with sex and sexuality, moving past that into talking about sexual health is bound to be filled with challenges and tensions, especially within a conservative or religious community; queer and trans sexual health then become an almost impossible conversation to have given the inherent discomforts that exist with that topic. It is important to recognize that heteronormativity goes hand in hand with LGBTQ2S+ erasure: the former positions heterosexuality as the norm, while the latter denies the existence of non-heterosexual and non-cisgender identities. Queer and trans individuals have long existed in rural areas, yet their needs have often been made invisible due to their categorization as 'less-than', or even worse, undeserving; it would be difficult for a healthcare provider to talk about and be knowledgeable of someone's healthcare needs if they do not even see their identity as being valid.

Heteronormativity is an extremely common finding in LGBTQ2S+ research as it is embedded into the very fabric of society, with heterosexuality being the standard while every other way of being is othered (Ussher, 2009). So, in a way, being LGBTQ2S+ in a society that does not approve of this so-called deviance is an act of resistance. Yet this does not come easily, particularly when lives are at stake because of the inaccessibility of safe healthcare. LGBTQ2S+ people are thus stuck between a rock and a hard place: how can they be their authentic selves -which ought to be every person's inherent right- while battling discrimination and oppression within a setting -healthcare- that, again, ought to be a right, and not a privilege to access. Moreover, if queerness is being sanitized to get rid of anything related to sex and sexuality, then how can it be expected of a queer person to feel comfortable discussing their sexual health with a healthcare provider who themselves are uneasy discussing sex and sexuality? A negative societal understanding of queerness affects both the LGBTQ2S+ community and the healthcare providers: the former through internalized queerphobia, and the latter through queerphobia and heteronormativity.

### *b. In Healthcare*

While discrimination was experienced in the participants' lives more broadly, they also provided more specific examples of how this carried over into their experiences of healthcare through heteronormative attitudes coming from their healthcare providers. One participant explained:

> *"It has been nearly impossible to get adequate sexual health care ... because doctors assume heterosexuality".*

This participant went on to share that this assumption was based on how the doctors had come across, both personally and through their interactions with clients. A strong example of this was exemplified when a physician refused to provide general medical treatment to women unless they took a pregnancy test that was unrelated to their treatment, despite the women saying they had never had sex with a cisgender man. In the participant's words:

> *"People indicated that when they go to (access healthcare) even just for general medical stuff, they got refused treatment unless they complied with*

> *having a pregnancy test, despite saying, you know, I've never slept with a man, I'm a lesbian".*

These kinds of assumptions, which are rooted in heteronormativity, made accessing services incredibly difficult for LGBTQ2S+ people. These experiences resulted in feeling invalidated, not heard, and seemingly not trusted to be telling the truth. This behaviour from a medical professional thus communicates that they have a narrow view of how certain protocols need to be expanded in order to ensure that their clients feel safe in an already-intimidating setting.

Numerous participants discussed how going through negative experiences of heteronormative assumptions resulted in barriers to seeking care. Many participants shared how lack of safety in the context of receiving healthcare services was experienced as traumatic. Oftentimes, the experiences were so traumatic that their effects were long-lasting. One participant explained:

> *"A lot of them won't (access services) because they've been so, especially for queer and trans folks, like, being so traumatized by the healthcare system that a lot of them are preferring to just not."*

This finding is particularly troubling since not accessing healthcare services such as sexual healthcare could be detrimental for LGBTQ2S+ individuals, especially those populations who are at higher risks of contracting HIV and other serious STIs (Campbell, 2013).

When doctors assume heterosexuality, they effectively erase a client's identity and indirectly communicate to them that they do not recognize or acknowledge their sexual and/or gender identity (Carrotte et al, 2016). Erasure then, can be understood as an act of ignoring or removing LGBTQ2S+ identities from the mainstream; the term historically originated in academic literature as bisexuality erasure within LGBTQ2S+ communities (Ghabrial & Ross, 2018). Through assuming heterosexuality, healthcare providers are reinforcing normative ways of being and potentially indirectly reinforcing a client's internalized queerphobia, which could lead to a slew of negative thoughts and behaviours. Heteronormativity also gives way to other forms of queerphobia such as the blatant transphobia that healthcare providers could exhibit. As one participant explained:

> "*I was identifying as non-binary and she thought that that was, that it didn't make sense. She also wouldn't use pronouns or preferred names, and I could see it written on her sheet, but she like refused to use it."*

The refusal to use the participant's correct name and pronouns was not only disrespectful, but also made the participant feel uncomfortable and invalidating of their identity. It is one matter to plead ignorance of someone's pronouns, yet an entirely different matter to be purposely oppressive towards a client who has made it clear how they would like to be addressed. As the participants mentioned, it takes an immense amount of strength to inform a healthcare provider -who is in a position of power- what one's pronouns are and to ask for them to be used, and yet that fortitude and resiliency are not often respected nor seen.

The participants also discussed how their queer and trans relationships were not always honoured or seen while they were attempting to access healthcare services. One participant shared their story:

> *"I tried to bring (my partner) in with me, and in the waiting room, (the healthcare practitioner) kept saying, your friend can wait outside, and I was like that's not my friend, that's my partner, and I'm allowed to have my partner come in with me, um, this went back and forth, close to five minutes, like your friend can wait outside, you don't need someone."*

Despite being corrected a handful of times that the person was their partner and not their friend, the healthcare practitioner ignored the participant's words and continued to either assume they were lying, or blatantly disrespecting their relationship and their request to bring their partner in with them. Heteronormative assumptions and norms were present when the healthcare practitioner addressed the participant's partner as their friend, but queerphobia maintained their unacceptable treatment of a client, despite being corrected on their assumption numerous times.

Discrimination in the form of heteronormativity, queerphobia and transphobia has been shown to be a major deterrent to accessing healthcare services (Alencar Albuquerque et al, 2016; Carrotte et al, 2016; Hsieh & Ruther, 2017; Lim, Brown Jr, & Sung Min, 2014; Ussher, 2009). It is not strictly a characteristic of small rural areas but is widely predominant in large urban and metropolitan cities as well, such as the Greater Toronto Area (Scheim & Travers, 2017). As will be discussed subsequently, experiencing LGBTQ2S+ discrimination in general healthcare settings means that accessing some of the most sensitive services, such as sexual healthcare, will mean experiencing greater challenges and difficulties because of an LGBTQ2S+ identity.

### *c. In Sexual Healthcare*

Based on the participants' stories of heteronormativity, queerphobia and transphobia in general healthcare settings, it is not surprising that these forms of discrimination permeate their way into more specific healthcare services such as sexual health. For example, one participant shared:

> *"I (was talking to a student) who had an experience, who's a lesbian, went to (local healthcare provider) for a, they didn't say what, something that has to do with sexual health, a problem she was having. The doctor was like asking questions and she said no I've never slept with a man, I'm a lesbian, and the doctor was like (high-pitched voice), oh! And you're a (college) student! Good for you! And went into this whole like, he couldn't believe that she was a lesbian and a (college) student. Needless to say, she never went back."*

This story touches on multiple issues at once, mainly queerphobia, the heteronormative assumption that all college students must be straight, and a general lack of understanding of what being LGBTQ2S+ even means. What makes this experience uniquely disturbing is that there was an element of surprise displayed by the healthcare provider that colleges would even allow LGBTQ2S+ individuals onto their campuses in the first place. It is not a lot to expect a healthcare provider to understand that human beings are not one-dimensional and can hold multiple identities at the same time; it is shameful that this is something that still needs to be explained to healthcare professionals.

Oftentimes, LGBTQ2S+ communities appear small, even in larger cities. This could be particularly problematic in rural areas because word usually gets around about the kinds of terrible experiences that people have encountered. This lack of anonymity further discourages LGBTQ2S+ individuals from potentially seeking sexual healthcare due to concerns about safety. This concern emerged as a critical issue facing the participants as they discussed the challenges that they would then feel when attempting to refer their LGBTQ2S+ clients. It was clear that many of the participants were wary about referring their LGBTQ2S+ clients anywhere due to their view that that no place was safe. One participant elaborated:

> *"I often find myself in a position where if, queer (folks) are coming to me to try to find sexual health services, I have nothing to say to them, because I don't want to send them to the (local healthcare clinic) because I know exactly the kinds of problems that (the other participants) have talked about, I know so many problems there, it doesn't feel like an OK referral for me to make."*

Unfortunately, this was the sentiment that was expressed by the vast majority of the participants, where some have chosen not to refer their clients anywhere because they had made a referral once that had turned out to be harmful for their client. Another participant added:

> *"I don't really feel comfortable referring anybody anywhere anymore, just because I was the one that had (made a referral that had gone badly)."*

The participants expressed that they did not want to send LGBTQ2S+ individuals anywhere that might result in a potentially harmful experience taking place. Despite being well-connected to community resources, most of the participants had challenges identifying safe spaces to refer their clients. When it came to safe referrals, the participants explained that they would rather send individuals out of town to reputable

LGBTQ2S+-safe services, despite the unique barriers that those options present.

The participants also emphasized that accessing sexual healthcare is not a spur-of-the-moment decision, especially for LGBTQ2S+ people. For example, one participant explained:

> *"If someone is already like, maybe thinking about getting tested for 6 months, 8 months, 2 years, they finally make the call (to get tested) …"*

The participant was explaining how sensitive of a topic it is for someone to seek out sexual healthcare, especially if they are already aware of the unsafe climate they may encounter for being LGBTQ2S+. Consequently, decisions to attempt to access sexual health care are often dwelled on for a substantial period of time before attempting to engage with that system. Hence, when an LGBTQ2S+ person finally musters up the strength to access these services, being met with unsafe and unknowledgeable healthcare providers is an extremely disappointing and potentially harmful experience, rendering them unlikely to re-engage with that system, as has been demonstrated by previous quotes and stories.

Aside from being associated with people in the field who could refer to or point out the services, participants discussed how an LGBTQ2S+ identity made it even more challenging to access sexual health services. Participants highlighted the ways that people from historically marginalized communities were likely to have an even more difficult time accessing sexual health services, such as queer and trans people of colour (QTPOC) and people living with disabilities. Participants weighed in on this issue:

> *"I know that there's a huge amount, there's no information basically going to people with disabilities period, if they're queer or trans, there is absolutely no information going to them."*

And,

> *"It's hard enough for a queer white person to find stuff."*

The participants were clearly aware of how both white privilege and able-bodied privilege were so intricately tied with service access, and they were forthcoming about how being in a white able body made this access marginally easier, albeit still taxing. The conversations were not limited to just focusing on disability and race, but also extended to talking about Indigenous communities, working class folks, and immigrants. These findings are consistent with other research that demonstrates how heteronormativity, queerphobia, and transphobia can result in systemic barriers to accessing sexual health services (Alencar Albuquerque et al, 2016; Carrotte et al, 2016; Keuroghlain, Ard, & Makadon, 2017; Mulé et al, 2009). Similarly, in this research, the participants made it clear that these issues continue to result in barriers to accessing sexual health services for LGBTQ2S+ individuals in their community. When living as an LGBTQ2S+ individual with multiple oppressed identities, such as living with a disability or being a QTPOC, the literature is also consistent with the fact that accessing sexual health services comes with even more added disadvantages (Gilbert & Rhodes, 2014; Hsieh & Ruther, 2017).

### *d. Service Providers (Mis/Un) Informed on LGBTQ2S+ Sexual Health*

Given the concerns about the lack of safe spaces to refer clients to for sexual health services, it was expected that one of the reasons for this was due to the participants witnessing how their healthcare providers were ill-equipped at providing them and their clients with adequate sexual healthcare. For example, a particularly pertinent area of sexual health knowledge that all practitioners who provide sexual healthcare should be aware of is the availability of PrEP, which was explained earlier as a drug that has been proven to reduce HIV incidences. While PrEP should be available to anyone at risk of HIV, it is most widely used amongst queer and/or trans individuals as one way to prevent HIV transmission. However, as one participant shared:

> *"When I mentioned PrEP at the (local healthcare provider), they didn't know what that was".*

The above quote was from a community worker inquiring about PrEP, which speaks magnitudes as to how poorly equipped this local healthcare provider was to be providing LGBTQ2S+ individuals with adequate sexual healthcare. The health care provider's inability to engage in this discussion stemmed from their lack of knowledge around LGBTQ2S+ sexual health. It is extremely important for healthcare providers to be aware and up-to-date on newer drugs that are being used to reduce HIV and STI transmissions because these drugs can save lives. However, the only way that people can benefit from drugs like PrEP is if their healthcare provider is not only knowledgeable and informed of their effectiveness, but also physically has access to these drugs. After mentioning that the local healthcare provider did not know what PrEP was, the participant explained how they are entirely unable to find a single healthcare provider in the community who carries PrEP, making it impossible to locally refer anyone who would benefit from the drug. Moreover, there are services such as point-of-care testing -a rapid HIV detection test that requires a finger prick as opposed to drawing blood- that are entirely unknown to the very practitioners who ought to be performing them. The participants knew that their area was equipped with the materials for this particular service, and yet practitioners were not offering it to clients. One participant explained:

> *“So they’re not even offering that service. Like you need to know about it in order to access it, essentially.”*

The focus group expanded on the above quote by wondering how an average community member could seek sexual health resources and supplies if they are not even known to their healthcare provider. One common example that the participants shared was how many healthcare providers they encountered who either did not know what dental dams were, or where they could get them locally; one healthcare provider, upon being asked about dental dams, responded by saying that “*we don’t do any dental care here, actually”*. The participants pointed out that while male condoms were widely available, dental dams were not– communicating that healthcare practitioners that deliver sexual health services do not know about, care about, or think about sexual health protection in this way. It is important to mention that the lack of practitioner knowledge of sexual health resources and supplies is not simply the fault of the individual practitioner but is the fault of a larger heteronormative system at play that normalizes heterosexual resources and supplies and marginalizes those that LGBTQ2S+ communities need (Hubach et al, 2017). A heteronormative societal understanding of sex and sexuality communicates that LGBTQ2S+ individuals are not deserving of appropriate sexual health information, resources, or supplies, further pushing them into the margins of society. It becomes evident, then, how this cyclical pattern continues: dental dams are not well-known in general; LGBTQ2S+ individuals are unaware of them; healthcare practitioners are either uninformed of their presence or choose not to carry them; thus, LGBTQ2S+ individuals continue to not use a resource they are unaware of that could benefit them.

Knowledge of HIV and dental dams are not the only barriers that the focus groups discussed. There were extensive conversations about healthcare providers believing that some members of the LGBTQ2S+ population either do not require certain medical tests or are forced to take unnecessary ones. A participant shared their story:

> *"It has been nearly impossible to get adequate sexual health care … because they think that lesbians don't need paps, (and) because they always do this thing where they force you to have pregnancy tests that you don't need, um, which makes it difficult to, you don't even want to access at that point that they're going to force you to take a pregnancy test".*

The assumption exhibited in the above quote is that the healthcare providers believed that, unless someone was having heterosexual penetrative sex, that they do not need to have a pap smear performed, which is medically false information (Alencar Albuquerque et al, 2016; Power, McNair, & Carr, 2009). Moreover, forcing pregnancy tests onto lesbian and bisexual women who have never had sex with cisgender men, as the above participant was discussing, invalidates their sexual orientation and communicates to them that they are not believed. This extended into the actions that participants had to engage in to ensure that they did get their health needs met. For example, as one participant shared:

> *"They were like, well have you done this, have you done that, well I don't really think that you need it … actually tried to talk me out of it multiple times, like I'm sure you don't need this, so then I was like, no, I feel like I do, because I had had an encounter with somebody, but let's say I hadn't had an encounter with somebody that I knew had an STI, would I then have pushed my doctor to go with it, probably not."*

Participants talked about their own experiences of having to advocate for themselves to get necessary tests done that they knew they needed. Again, the above participant was a service provider who knew how to confront their healthcare practitioner, raising questions about the degree to which an average community member would be able to advocate for themselves in a similar situation. This concern reflects the experiences of many of the participants in this study, articulating how uninformed healthcare providers do not only make it difficult for LGBTQ2S+ individuals to access sexual health resources, but may also put their lives in danger if they are not given proper medical attention.

Lack of information about sexual health resources is mirrored in the literature, especially when it comes to HIV education, prevention, and support (Hubach et al, 2017; Scheim & Travers, 2017). It is crucial to think about where this lack of knowledge stems from: is it that healthcare providers are not being taught this information in school? Is there a lack of continuing education opportunities specifically relating to LGBTQ2S+ health? Or is the onus on the healthcare providers to seek out this information in order to be better practitioners? Regardless of which it is, it has become exceedingly clear that something needs to be done to remedy the lack of LGBTQ2S+ health knowledge that healthcare providers have demonstrated.

## 2. Barriers to Accessing Sexual Healthcare

It has been established so far that accessing sexual healthcare as an LGBTQ2S+ individual living in a rural area presents its own unique challenges and hurdles due to heteronormativity, queerphobia, and transphobia. It is difficult to tease out these forms of discrimination from the fabric of everyday life, making them a constant societal undercurrent regardless of the context. Thus, bearing that in mind, it is equally imperative to look at some of the systemic issues that affect service access, such as the presence of red tape that prevents service providers from being able to fully support their clients. A quote that demonstrates this well is:

> *"Because people can't even navigate it when they're service providers, so obviously anyone in the general population is not getting anything on their own."*

The participant was discussing how unmanageable the system felt to the very people working in it that they could not imagine how a community member, who is not connected to an agency or a person in the know, would be able to access services. Another systemic issue that is becoming more obvious is the presence of point-of-contact people, who are very specific service providers and practitioners who have been designated as safe by and for LGBTQ2S+ individuals to seek services from. The participants also spoke in great detail about how confidentiality and safety are not always guaranteed in a relatively small rural area, adding an extra layer of complication to accessing a sensitive service. Due to a number of factors, service providers end up referring their clients to LGBTQ2S+-safe services that are out of town, thus avoiding many obstacles but also creating others. Each of these topics will be discussed in depth in the following theme.

### *a. Systemic Red Tape*

The participants were highly critical of the sexual healthcare system that they operate in and discussed the multiple barriers within the system that made it challenging to both refer and to access sexual health services. A common barrier that was shared amongst the participants was the presence of "red tape" that results in barriers to accessing sexual health services and in their process of referring. One of the consequences of red tape at a professional level was the frustrations that resulted in the service providers feeling completely helpless in the face of the barriers. As one participant explained:

> *"There's a lot of individuals in agencies who are really trying, who want to do the right work, but they're working within a system where they're just, there's so much red tape, there's so much stifling of ideas and creativity, and wanting to do things … they're just working within a system that doesn't allow them to do what they want to do."*

Another participant added how working with co-workers horizontally within social or healthcare services may not yield results because the issues are rooted in the larger system. They explained:

> *"And the people we're engaging with aren't people making decisions, right, they're front-line workers, and even if they're very excited, they still have to get approval (to make something happen from those in charge)".*

In addition to feeling restrained in their work, participants also felt that this resulted in them carrying the brunt of the system on their backs as they attempted to connect people to the right resources. Examples of carrying the brunt of the system include having to go out of their way to get the right contacts, doing tasks outside of their job's requirements, and accommodating in-need clients who may not meet their mandates. The participants agreed that this is not sustainable, and that those individual service providers are likely to burn out if they continue to try to find creative ways of working around the red tape. The participants also discussed how the barriers that they face within the system cannot be tackled individually and should not be the responsibility of any one person to solve. A participant explained:

> *"Sometimes there are things that you can take on and sometimes things that you can't, and the issue in that is located in the system not in the individual's capacity to constantly be changing the system".*

This raises concerns about the red tape that LGBTQ2S+ individuals encounter when they are in need of sexual healthcare, particularly in circumstances where they are not connected to service providers who are knowledgeable about where to go for safe services.

While the literature does not explicitly tie the links between LGBTQ2S+ individuals' difficulties in sexual healthcare service access to complicated systemic barriers, it does discuss how lack of LGBTQ2S+-inclusive policies make service access more difficult due the red tape involved.  This is concerning because systemic issues within healthcare settings are fairly well-disguised and are not apparent to service users, but they are relatively clear to service providers who work within the system and can see the big picture. Systemic barriers are covert and unsuspecting because they are buried within policies, antiquated processes, and oppressive protocols that have not been altered to fit with an evolving society, thus rendering these barriers nameless.  Through identifying the parameters of the red tape within the system, we can then start to understand how it functions to keep people from accessing services and work towards dismantling those barriers.

### *b. Confidentiality and Safety: Everybody Knows Everybody*

As participants have mentioned, sexual health is a sensitive topic to broach with healthcare practitioners. To many LGBTQ2S+ individuals, discussing sexual health within a small community may pose many risks and challenges that result in barriers to accessing services. One barrier is that of maintaining confidentiality and anonymity. A participant of this research explained:

> *"It's hard to talk to your doctor, because, as much as confidentiality is supposed to be a thing, I don't think that a lot of younger people feel, or even older, like I have some clients who have had their (health) status disclosed to family members, who have been disowned by their family … so I think, and usually if like, it's your family doctor, perhaps it's your family doctor since you were a child, so they know your parents, your siblings, so if it's something that you can't even tell your parents or your siblings, you go and talk to your doctor, you don't know if that information is safe with your doctor."*

Given that queerphobia and transphobia make LGBTQ2S+ individuals fearful of having their confidentiality breached, some agencies are attempting to address these concerns by providing inclusive services. However, the challenge with this is how people are perceived when accessing a service that has a taboo label or reputation attached to it. The participants agreed that a label is a powerful thing, especially in a small community where word travels quickly. One participant explained:

> *"So as much as there are some agencies trying to provide the services, I think that there may be agencies that people could be fearful of accessing as well because of what they may labeled as".*

This a particularly tricky issue since even if services are trying to be inclusive and welcoming of LGBTQ2S+ clients, they may not be seen as an accessible service because of how their services are perceived by the community. For example, if an agency that is situated in the middle of a conservative and religious town largely caters to a vulnerable population -such as the LGBTQ2S+ community-, then anyone accessing this agency may be associated with the LGBTQ2S+ label, whether that is true or not. However, regardless of the truth, that label may carry harmful consequences to individuals because of the heteronormative and queerphobic societal climate.

This finding about how confidentiality determines whether LGBTQ2S+ individuals access sexual health services or not is in line with what Gottschalk (2007) found in their study of rural LGBTQ2S+ individuals, where confidentiality was a major deterrent to coming out or accessing services from professionals. This issue does not only come up with respect to family doctors: participants discussed how being seen accessing certain services could be detrimental to LGBTQ2S+ individuals given the smallness of rural cities. As Higginson (2012) also noted, worrying about confidentiality is not an uncommon problem in rural settings: their research in a nearby region found that youth expressed concerns about accessing sexual health resources for fear of being seen by people they know. This issue is doubly concerning for those LGBTQ2S+ individuals who may not be out to everyone in their community. This is a troubling finding since it makes it even more difficult for an already-marginalized population to seek help.

According to Gottschalk (2007), LGBTQ2S+ communities in rural areas end up creating informal networks in order to interact with one another and exchange resources. The participants of this research have echoed the same strategy, explaining that they belong to and are aware of many informal networks that exist in their community by and for LGBTQ2S+ individuals. These informal networks act as support systems for people seeking access to different resources, and they also help connect people to one another, lifting the social isolation many LGBTQ2S+ individuals feel in small towns. However, as mentioned by Gottschalk (2007) as well, these informal networks are often difficult to find if one is not well connected, posing a problem for newcomers into the area and those who are not publicly out.

### c. *'Single Point-of-Contact' Person & Referrals*

#### i. *The Connector*

As a result of the lack of safety caused by queerphobia, heteronormativity, and uninformed healthcare providers, LGBTQ2S+ communities have unofficially designated certain people to be safe, or the 'single-point-of-contact' person. The service providers who refer to point-of-contact people are the connectors. These service providers are the ones who LGBTQ2S+ individuals would turn to in order to obtain a referral to a safe healthcare practitioner. These connectors may be a part of the LGBTQ2S+ community or allies with a strong vested interest in facilitating service access for the community. One of the main methods that the participants -who are connectors themselves- used to get the word out about point-of-contact people was word of mouth:

> *"I find if it's kind of word of mouth and they've been referred by a person that they trust and they say that this is a safe place to seek care, then it goes quite well."*

The participant talked about how crucial it was for them to refer to a single safe person as opposed to an unsafe agency. Another participant talked about the potential risk involved in referring a client to an agency that has a safe provider in it but getting to that person may be challenging if the agency has multiple steps to go through. The participant explained:

> *"So unless you have another avenue to be able to connect with (a safe healthcare provider), we may miss you, like we may lose you in that process."*

Aside from word of mouth referrals to point-of-contact people, LGBTQ2S+ clients need to first see that the connector is someone who is trustworthy and safe before they are able to trust the referral itself. This trust process is often done through more extensive and extended word of mouth referrals, such as through trusted friends. Even more specifically, some participants discussed how they have reverted to very particular referrals; one participant mentioned:

> *"I like never really refer to, like I don't refer people to (person)'s program, I refer them to (person). So the difference between referring to, like yeah, just refer to the … program and tell them at the … program, like it's very specific to (the person)."*

The participant further explained how they encourage clients to mention the participant's name when connecting with the referral so as to make the connection personal and intentional.

The participants voiced their concern about how fragile the system seemed to them, so much so that if someone who is a connector burns out because of the constant strain they are under, the whole system would collapse, particularly affecting vulnerable clients. One participant elaborated on this point, saying:

> *"The systemic (support) isn't there, so as soon as that person goes, it all falls apart, and I think that's sort of the theme that we keep talking about and I keep seeing is that, that piece it's like, systemically it's not there, so it's about an individual, and if that individual goes, it all goes."*

This is a particularly pressing matter in smaller communities where there are less resources available to begin with. Because the resources and the people are stretched so thin, the absence of a crucial person in the system could mean dire consequences to those connected to that person. As the participants said, the system is simply not equipped to stand alone without those key players propping it up on their shoulders, usually at the expense of their own mental, physical, and emotional health.

One of the results of systemic barriers that stifle service providers' ability to do meaningful work is that LGBTQ2S+ individuals need to be well-connected in order to be informed of appropriate services to access. One participant elaborated:

> *"I think also it's because of a lack of knowledge, people don't even know where to turn, so when I talk to people, I try to give them ideas of where to go, but because there is such a lack …it's really kind of like, it's almost like friend to friend information, again, it's service provider to service provider information".*

The participant explained how, because they are fairly well-connected in the community, they try to be a connector for people who need to access services. The above quote demonstrates how important it is for LGBTQ2S+ individuals to 'know the right people' if they want to access LGBTQ2S+-safe services.

Participants who are connectors talked about how, in order to ensure that their referral was as safe as they explained it to the client to be, they needed to find a way to get their client to the designated safe point-of-contact person, as opposed to taking a risk of losing the client within the broader program or agency. This is exhibited in the participants' quotes that show how person-specific their referrals have become. Many participants spoke about the difficulties that they encountered in being connectors, such as finding creative ways of referring people who may not fit the criteria, but they still recognized the role as being a lifeline for LGBTQ2S+ people who are struggling to get connected to healthcare services. Having connectors in healthcare is necessary for those LGBTQ2S+ individuals who are not socially connected to an LGBTQ2S+ community where they could gather insider information.

### ii. *The Advocate*

The designated advocate is the LGBTQ2S+-safe healthcare or service provider who gets referred to by the connectors and knows where the loopholes exist in the system. While these people are few and far between, they are of immense value and importance to the LGBTQ2S+ community. Like the connectors, they may themselves be a member of the LGBTQ2S+ community, or an ally with a vested interest in fulfilling a need in sexual healthcare for a vulnerable population. The participants emphasized the importance of having advocates in the system who could facilitate access to LGBTQ2S+-

specific sexual healthcare and supplies, but they also touched on what happens if and when those people leave. One participant explained:

> *"There used to be a person from (a local healthcare service) who sat on (the Collaborative) who was very helpful, and got us like, a full year's supply of condoms and dental dams every year for Pride. And then (this person) left. And (the local healthcare service) didn't, they only gave us condoms, so we fought with them and fought with them and I think that year we didn't get any."*

The above quote demonstrates the fragility and unpredictability of the system that was discussed earlier in the section about systemic red tape. The participant suggests that the knowledge and resources that one person has access to can become specific to that one individual. While this is not at all that one individual's fault, it is the result of the system that allows this process to take place. The consequences of this include pigeonholing a wealth of information into just one person's role; overloading one person with an unmanageable amount of work since they hold the necessary knowledge and/or resources; and running the risk of losing that person to burnout, and thus losing important knowledge and resources.

In order to address some of the structural barriers, one participant suggested the importance of identifying the right people with the right kind of mindset in order to create a catalyst to get important work done in the community. This idea emerged through a focus group conversation about how difficult it was for a few of the participants to get a pop-up sexual health clinic started and how laborious it was becoming to try to convince other members of a collaborative that it was a good idea. They explained:

> *"And again, down to just two people who just happen, who I happen to stumble upon, who just had a different mindset than perhaps some of the other people there, like we're going to make this happen, and if I had never met those two people, I don't think that we would (be getting the same kind of work done)."*

Therefore, when the participant came across those two key players, the process became easier and better streamlined since the advocates were already armed with the appropriate knowledge and resources to get things moving.

Given the systemic barriers and the red tape discussed at the beginning of this section, it is not surprising that that such a constrained system would produce point-of-contact people within it. Through the lack of the accessibility and availability of sexual health services for LGBTQ2S+ individuals, word of mouth of those services prevails, and designated advocates in that system become the go-to individuals for people who may otherwise get lost in the complicated web of healthcare. However, as mentioned prior, the implication of this kind of system is that not everyone gets to benefit from it; LGBTQ2S+ individuals who are not well-connected socially, such as newcomers to the community, end up falling through the cracks.

Lastly, an important issue that emerged within this discussion was the value of ensuring point-of-contact individuals were not isolated and that they had a space to connect to one another. The Collaborative is a good example of how point-of-contact people come together to share ideas and learn from each other. One participant elaborated:

> *"I actually think that informal things happen between like us and service providers too, right. So like I'll ask someone around this table, like what doctor, what (specialist), or whatever, that you need, would you send someone to that you trust, yeah, a lot of that happens amongst us too."*

Hence, one way of addressing isolation was through the process of networking. Participants discussed how they have found it useful to bring point-of-contact people together in the form of volunteer groups such as the Collaborative where they could build relationships and tackle systemic barriers collectively. It takes a lot of time, effort, and commitment to take on a volunteer position that can be as demanding as one's work, but the participants of the Collaborative all view the necessity of the work that they do, thus making the work all worthwhile.

The phenomenon of the single point-of-contact person is not well documented in the literature; my personal speculations are that it is has not yet been taken up as an emergent issue, or the terminology used to describe the point-of-contact person is not yet standardized, making many authors write about this phenomenon using different words and descriptors. However, what does exist in the literature are articles discussing 'key workers', who are described as dedicated workers who work one-on-one with vulnerable clients and tend to the majority of their needs (Brogaard, Jensen, Sokolowski, Olesen & Asbjørn Neergaard, 2011; Parr, 2016). While this definition does not encompass who single point-of-contact people are in this research, it creates dialogue around the potential for key workers to morph into single point-of-contact people because of an emerging need for them in an ever-restrictive care system.

### *d. Transportation & Out-of-Town Sexual Health Services*

Participants discussed the ways that some LGBTQ2S+ individuals were able to access services beyond their rural community. One way that this was made possible was by owning a vehicle that could transport individuals to services in nearby large urban cities. It was noted then, that owning a vehicle comes with many opportunities and privileges that otherwise would not be entirely feasible. As one participant mentioned:

> *"A huge barrier to access in terms of transport (is) actually being able to get physically to the (area) where those services are provided."*

The participant was explaining how public transportation does not fulfill the community's needs of getting to certain areas of the city and is thus an unreliable method of transportation. Without one's own vehicle, the options are fairly limited regarding which areas are accessible and which are not.

The participants discussed how they often refer to sexual health services outside of their community when they do not think that the local services are safe, accessible, or LGBTQ2S+ inclusive. However, being able to access sexual health services outside of one's community is heavily tied with privilege, specifically socioeconomic privilege, as the participants noted. They discussed the reality of how their clients were not being able to access sexual health services that required travel outside of the rural city. One participant noted:

> *"Yeah it's a lot of privilege to be able to (travel for services). So, if you*

> *can't do that, then you're stuck here either dealing with really problematic health services or just not accessing."*

Some of the participants spoke about their experiences trying to make out-of-town services more accessible for their clients, stating that:

> *"There's just there's almost nothing to say, so then you go to move towards, let's check out (bigger city), let's check out (reputable service provider) in (metropolitan city), let's think about the ways in which we can get you transportation so that geography isn't as much of a barrier, but that to me really ends up being a lot of the things that then we're trying to work through, is like how do we get them to other places so that they can actually access the care."*

The participants explained how they felt like their hands were tied when they were trying to refer their clients to somewhere accessible not only with regards to LGBTQ2S+ proficiency and safety, but also geographically. If clients are unable to make it to a neighboring city for services, then they are stuck, as the participant mentioned. The participants discussed how upsetting it was to not be able to refer their clients to local resources, further explaining how they often felt personally responsible for connecting their clients with the services that they needed, and yet could only do so much to make these services more accessible when the barriers seemed insurmountable. Some participants even mentioned that they did not feel like they were adequately performing their jobs because they could not refer their clients to a local healthcare provider that they trusted would be safe. For some, travelling to access services is a necessary but doable evil. And yet for others, it is an obstacle that is not worth the costs associated with it.

The most relevant research finding that echoes how transportation is a barrier to services is found in Higginson's (2012) study, where the research's participants found transportation to be restrictive to their access of sexual health services in a rural area. This finding is particularly significant to this research because Higginson's (2012) study is geographically adjacent to this research's geographical area, thus strengthening the findings. Moreover, Hsieh and Ruther (2017) found that not having transportation constituted a barrier for LGBTQ2S+ individuals not accessing healthcare services. The last piece of literature that supports this finding is that of King and Dabelko-Schoeny (2009), where their LGBTQ2S+ participants described transportation to be the "hardest obstacle" when it came to accessing healthcare services; some even described it as affecting their physical and mental health. This finding stresses the need for establishing LGBTQ2S+-safe and accessible healthcare services in rural areas that are evidently in dire need of them.

### 3. Community Responses & Strategies

As a response to a lack of safe and inclusive LGBTQ2S+ sexual health services in the community, the participants discussed how they use specific tactics and strategies to fill in the gaps that they see. They talked about how forming working collaboratives that focus on the LGBTQ2S+ community is a big avenue for change. Out of the collaboratives come strategies for grassroots initiatives that aim to fill the community's needs for specific services and resources. Lastly, the formation of informal networks is another strategy that is used, where LGBTQ2S+ members help one another surpass barriers and access services that may otherwise be out of reach or unknown to them. It is important to be aware of the fact that central to all of these strategies and responses are point-of-contact people who are key players in mobilizing resources responsible for change.

### *a. Collaboratives*

Through recognizing the gaps that exist in the community, the participants discussed how a number of service providers mobilized and formed a collaborative that specifically deals with local LGBTQ2S+ issues; this group has been addressed as the Collaborative throughout this paper. The participants agreed that the Collaborative played a key role in the community through taking direction from LGBTQ2S+ individuals - many of whom sit on the Collaborative- about what sorts of changes are needed. One participant elaborated:

> *"So things … like (the Collaborative), or other committees, is where I think the real work is actually getting done, the things that these agencies are funded to do or don't have the time to do that the people from those agencies are like, hey I have a vested interest in this, they come together and this is actually where the bulk of the work is trying, at least, to get done".*

A number of the service providers who sit on the Collaborative are point-of-contact people themselves, making the Collaborative a perfect space for them to connect with one another. Some of the initiatives that the Collaborative is responsible for include: creating posters to advertise hidden services, hosting informative workshops to learn about the work that is being done in the community, and supporting other collaboratives in getting connected with appropriate resources so they could do the work in the community. It is unfair that this work has fallen on the shoulders of volunteer-run collaboratives, when instead these tasks and services should be taken up by government-funded public agencies or should at least be generously funded to take on this work.

LGBTQ2S+ communities are notorious at creating their own resources in the face of adversity and exclusion. A textbook example is Muscolino's (2016) research about a community-led HIV prevention campaign that launched in Queensland, Australia, as a response to the area's rising HIV rates among LGBTQ2S+ communities. The campaign team followed the community's lead in creating a campaign that was owned by the community and was for the community. This initiative is an example of what type of work can be done through grassroots collaboratives that are invested in the community and its wellbeing.

### *b. Alternate Grassroots Services*

Other than making resources known to the LGBTQ2S+ community, the Collaborative also engages in creating needed resources and services through their sub-committees. The healthcare-focused sub-committee puts its efforts into initiatives such as ones that focus on sexual health and HIV prevention, education, and support. One participant explained a recent project of theirs:

> *"We're trying to create a bit of a resource (for newcomers to the area), it is pretty specific to HIV, we're talking to our clients and trying* to get *information, and so what we're trying to do is get at least a list of 3 to 5 doctors who aren't going to stigmatize HIV patients."*

The participant talked about how useful this resource would be for people who might be too afraid to access a healthcare practitioner without knowing if they were going to be knowledgeable about LGBTQ2S+ and HIV-related issues.

Excitingly, some participants discussed the possibility of hosting a 'pop-up' style sexual healthcare clinic that would be in a central and accessible location and would be LGBTQ2S+ friendly as well as anonymous. The participants speaking to this were members of the Collaborative and were the co-organizers of the initiative. Hosting this type of clinic would be immensely useful for some community members who then would not have to worry about making appointments (since it would be on a drop-in basis), being accidentally outed (since the location is a community centre), or even providing their legal name. If this type of clinic were to become successful and meet the needs of the community, then it could potentially open up endless possibilities for implementing the same model in rural areas across the province. Moreover, if it is indeed LGBTQ2S+-friendly, then those communities would be able to vouch for its accessibility through word-of-mouth.

### *c. Informal Networks*

Continuing the conversation about the importance of networking and collaboratives, the participants emphasized how crucial it was to be connected to one another in order to be able to find the 'grey areas' in the system that would allow for greater flexibility in getting people necessary resources. One participant explained:

> *"I feel like a lot of relationship-building in the community where we all have like a network where we try to, fit people in to whatever, like stretch people's mandates and stuff to make it work as much as we can."*

Going hand-in-hand with collaboratives, the participants further talked about "*broadening the spectrum*" of their work's qualification criteria in order to have more people be eligible to access those services. The participants found this to be a necessity since the healthcare system is so inaccessible for LGBTQ2S+ individuals that service providers are left with finding loopholes that would help them bypass or even avoid the red tape. Through having informal networks outside of working collaboratives who still work side by side with them, LGBTQ2S+ individuals who are service providers and community members can connect people to one another and refer them to the services that they need to access.

## 4. Conclusion: A Deeper Dive

The themes found in this research show that LGBTQ2S+ individuals living in rural areas experience unique barriers when it comes to accessing healthcare services, especially services as sensitive as sexual healthcare. While the theme heteronormativity, queerphobia, and transphobia was taken up by itself, it realistically cannot be teased apart from every other theme and subtheme that was discussed in this chapter. The insidiousness of heteronormativity is found in most social interactions because we live in a society that expects a cisgender and heterosexual identity while rejecting an identity that deviates from that norm, regardless of whether that rejection is active or passive.

The participants shared their stories of heteronormativity, queerphobia, and transphobia both as they have personally experienced them as well as how their clients have experienced them. They went into more in-depth detail about those experiences within general healthcare and sexual healthcare settings, and it became obvious that the barriers they experienced were similar to those explained in the literature: sexual stigma, marginalization of LGBTQ2S+ identities, and a general lack of understanding of LGBTQ2S+ sexual health needs were all dominant findings. These barriers not only create an unsafe environment for LGBTQ2S+ individuals seeking to access sexual health services, but they also reinforce the harmful stereotypes and judgements that are often put on LGBTQ2S+ populations. For example, there is a common societal perception that LGBTQ2S+ individuals do not exist in rural settings (Kazyak, 2011), alluding to the idea that services do not need to be tailored for them. Without appropriate and safe healthcare services, LGBTQ2S+ individuals are not encouraged to be out to their healthcare provider, thus reinforcing the misconception that LGBTQ2S+ communities only exist in large urban centres. This results in a 'catch twenty-two' effect that is dangerous in nature because it leaves many LGBTQ2S+ individuals in vulnerable situations and without proper care.

Continuing the conversation about barriers more comprehensively, the participants discussed several elements that make it difficult and oftentimes dangerous for LGBTQ2S+ individuals to access sexual healthcare. The presence of systemic ‘red tape’, described as ineffective bureaucratic procedures or protocols that limit a worker’s ability to help their clients (DeHart-Davis & Pandey, 2005), have made service providers’ work excessively more challenging when it came down to helping LGBTQ2S+ populations access healthcare services. The participants discussed how they are aware of so many service providers who continuously try to push the boundaries of their roles in order to do what is best for their clients but are held back by outdated and oftentimes oppressive procedures. One of the biggest challenges that come from having to navigate systemic red tape is the real potential for burnout. The participants were forthcoming about the difficulties they experience that come with constantly pushing against the system, such as dealing with more stress, potentially coming up against their role’s restrictions, and feeling like the amount of work ahead of them is insurmountable.

Another barrier that was widely mentioned was that of confidentiality and anonymity. Given that this research took place in a rural community, the participants talked about how ‘everyone knows everyone’, making it tricky for LGBTQ2S+ individuals to assess how safe it was for them to disclose their sexual and/or gender identity. The participants also spoke about how LGBTQ2S+ individuals are wary of being seen accessing a certain service that may be taboo, for fear of them being negatively labeled. This is difficult for well-meaning agencies that are trying to make services safe and accessible for LGBTQ2S+ populations but failing to do so because of the stigma that may come with associating with that agency.

Lastly, transportation was a major barrier that prevented LGBTQ2S+ individuals from accessing sexual health services, whether those were in their local community or elsewhere. Socioeconomic privilege was a big indicator of how likely it would be for people to access sexual health services in larger urban cities because having one's own vehicle necessitated it. LGBTQ2S+ individuals who were unable to afford having their own vehicle or to even take time off work to travel were unlikely to access out-of-town sexual health services; King and Dabelko-Schoeny (2009) found this theme to be predominant in their research as well.

Even though all of the barriers to sexual healthcare that the participants discussed are valid, important, and need to be paid attention to, one of them appears to be the most striking and deserves to be deconstructed further. The 'single-point-of-contact' phenomenon is not entirely unusual in rural areas and with marginalized communities, but it also should not be the norm. It is a position built out of necessity and fulfilled by those with a deep vested interest in the wellbeing of those they are helping. It is no easy job as it is an almost sure-fire way of getting burnt out if it is not managed properly. However, despite the desperate need for point-of-contact people and the gaps that they fill, it is worthwhile to look at this phenomenon from the point-of-contact persons' perspective. The following example is meant to communicate the experience of a point-of-contact service provider; some of the information is data, while some is my own analysis of the data.

As a 'point-of-contact' person who may be both a connector and an advocate, your job is comprised of multiple jobs amalgamated into one. You are heavily connected to others in the community and if you are a healthcare practitioner, many of your friends and colleagues refer their clients to you regardless of whether they meet your inclusion criteria or not. If they do not, then you try to stretch your mandate because you know the system is ruthless and will not accommodate this person elsewhere. You try to find loopholes in the system so as to ensure your clients can receive the resources that they need. Part of your role includes networking with services in the community, so you are aware of who does what; this means that you strive to be on good terms with people who you may need to refer to one day. You know you are a valued and important member of the community and that many people depend on you, and yet despite your role being gratifying, you worry about never having the option to leave your job for fear of removing yourself as a valuable community resource. You worry that whoever would be employed in your wake would not be as competent in the role and might give it up because of the hardships it brings with it. Moreover, other people tell you that they do not know what they would do without you, further reminding you that the consequences of leaving -or worse, burnout- would be grave.

The reason for the above example is to paint a realistic picture of what it means to be a point-of-contact service provider, with all of its positives and negatives. The example is not meant to be convincing of the importance of the role; on the contrary, the opposite is true. As valuable as this role is, it is unfortunately not sustainable. People need to be able to be promoted, take a leave of absence, or simply quit for a better prospect without feeling like they are letting people down, or worse, cutting off service access for those who are vulnerable. The system needs to have certain measures in place so that point-of-contact people are not created in the first place. Things like better public transportation, more centralized healthcare services, LGBTQ2S+-friendly and accessible sexual healthcare available everywhere, and up-to-date and competent healthcare providers are some that are worth mentioning. It has become obvious that the biggest problems this research has shed light on are systemic in nature, and thus need to be tackled on a systemic level, rather than an individual level, which is what has been occurring.

Aside from the challenges and barriers that LGBTQ2S+ individuals experience in rural settings when it comes to sexual health, it is still crucial to recognize the resiliency that people exhibit in spite of these challenges. Communities form collaboratives, informal networks, and grassroots services in order to combat the barriers that they experience, and that part of the story cannot be erased; it needs to be recognized and celebrated. The participants spoke of success stories, albeit infrequently, of their clients fighting tooth and nail to obtain the healthcare that they needed. Many of them advocated for themselves and their loved ones tirelessly, either until the system gave in and they received the care that they needed, or they carved a new path to tread. This level of persistence and tenacity is remarkable yet unrealistic to ask of everyone to exhibit: accessing needed healthcare services ought to be a right, not something to fight for.

# Chapter 5: Implications

Emerging from both my research process and findings are implications for social work practice and policy, social work education, and research. While it is important to critique the gaps and barriers, it is of equal importance to look at the potential solutions and resistance strategies that have been created as a result. Within a social work context, both this research and the literature demonstrate how our field can be a positive force in helping shift the current healthcare climate that is rife with barriers and misinformation.

## 1. Implications for Social Work Practice & Policy

### *a. The Potential of Collaboratives*

One of the biggest findings that this research has unearthed is the power and potential of collaboratives. Despite the challenges that they face, the collaboratives' perseverance shows a strong dedication to their community and to the change they want to incite in society. Due to the systemic barriers, the difficult-to-access resources, and an unsafe healthcare system for LGBTQ2S+ individuals, the participants quickly learned that they could accomplish the most through building relationships with one another and forming volunteer-run collaboratives aimed at filling the large gaps that the system had created. For example, Muscolino's (2016) CBR project on making PrEP available came purely out of a community need and quickly developed into a community-driven campaign that had the buy-in from a local non-for-profit organization. Collaboratives try to capitalize on overlapping mandates between the collaboratives and their own individual workplaces so as to be able to make some parts of their work paid. The work that the collaboratives do is tough, demanding, and constantly shifting, yet is incredibly necessary in the community. Remarkably, despite the seemingly insurmountable hurdles and the precarious nature of their membership, the collaboratives' work is tantamount to that of a small start-up charity or non-profit organization. Many collaboratives have codes of conduct, membership agreements, treasurers, workshop facilitators, and many more elements that regulate their work and give them enough of both structure and leniency to tackle the problems that their community faces.

However, there is a limit as to how much collaboratives can achieve within any given timeframe and with limited funds. Bailey and Koney (1996) explain that social workers need to be involved in both learning about and participating in collaboratives because social workers can play a key role in connecting multiple community stakeholders to one another to amplify their voices. Connecting people and agencies together could mean the potential for increased collaborative membership, more buy-in, and potentially more funding.

### *b. Creating LGBTQ2S+-Specific Policies*

Another gap in the system that is slowly being addressed is that concerning the creation of LGBTQ2S+ specific policies. Activists, academics, and social workers alike have historically been working on and continue to work on projects and initiatives that shine a light onto the outdated and harmful healthcare system that we exist in, making note of the fact that an adaptation of policies aimed at including LGBTQ2S+ populations would save many lives. When LGBTQ2S+ populations are not consciously thought of when developing policies, then they will inevitably come up against barriers when attempting to access services. It has been discussed previously that LGBTQ2S+ populations are almost entirely absent from social policy discourse; even if they are mentioned, their health is likely taken up through a disease-based approach rather than a social context and social determinants of health approach (Mulé et al, 2009). Mulé (2005) urges us to look at health and social service policies in a systematic way while paying close attention to the nuances in wording that marginalize LGBTQ2S+ populations. Unsurprisingly once again, heteronormativity is seen as the main culprit behind social policies that normalize heterosexuality and define the structures of society (Mulé et al, 2009).

The lack of LGBTQ2S+-specific policies has been going on for long enough for people to take notice and act against it. In 2009, a group of six Canadian LGBTQ2S+ individuals filed a human-rights complain against the Canadian healthcare system, claiming that, despite the abundance of LGBTQ2S+-specific data and recommendations, Health Canada has failed to implement any of them into their policies (Garro, 2009). The report that came out of the lawsuit also included a long list of health issues that plague LGBTQ2S+ populations because of their absence from policies (Garro, 2009). If LGBTQ2S+-specific policies were incorporated into mainstream protocols and procedures within healthcare settings, not only would they be life-saving, but coming across an LGBTQ2S+ individual would no longer be an anomaly; it would be normal. When standard procedures are developed while having LGBTQ2S+ health in mind, then

LGBTQ2S+ populations would no longer fear accessing healthcare services. As a result, LGBTQ2S+ individuals would be more likely to talk to their healthcare practitioners about sensitive and important matters that would make them lead longer and healthier lives.

## 2. Implications for Social Work Education

Social work education can occur in schools of social work classrooms, the field and through community-lead projects. These approaches to social work education can increase the capacity of students and community members alike in order to work towards improving access to sexual health services for the LGBTQ2S+ communities.

### *a. In Schools of Social Work*

It would be advantageous for schools of social work to then take the first crucial steps towards educating students and making sure they are prepared to fight and advocate for change once they enter the field. Schools of social work can take a number of steps to ensure that their students are well-equipped and ready to enter the workforce armed with the knowledge of how to enact and push for changes in the healthcare system. Since a large part of this research has been on the importance of collaboratives, it would be worthwhile to reflect on the process of integrating them into a social work curriculum. Bailey and Koney (1996) suggest introducing a course within the school of social work that focuses specifically on community-based collaborations, including theoretical underpinnings, scenarios to respond to challenges, and real-life examples of being a part of a collaborative. Moreover, students can take advantage of their placement opportunities and become involved in a community collaboration in order to get a more in-depth understanding of the inner-workings of the group. As a result, students would then enter the workforce with a thorough understanding of the system while also being well-connected to people already working on community projects.

Another strategy that schools of social work could implement is the development of university-community research collaborations, much in the form of CBR. Begun, Berger, Otto-Salaj, and Rose (2006) discuss how both parties have common interests and could thus tackle them together using one another's resources. Aside from experientially knowing that this approach is effective in producing long-term results, Begun et al (2006) explain how these forms of partnerships could open up many doors for smaller community organizations, especially in the realm of funding opportunities. A different approach to take with regards to university-community collaborations is the creation of new social work programs created specifically for nurturing community partnerships. Wertheimer, Beck, Brooks, and Wolk (2004) conducted a study that followed the creation of an MSW program that focused solely on developing community partnerships, despite the pushback that the school received from skeptical social workers. The development of the program reinforced the school's commitment to involving the community in its endeavours as opposed to separating academia from the community (Wertheimer et al, 2004). While not all social work schools could develop a similar program, Wertheimer et al's research demonstrated the importance of university-community partnerships within the context of equipping future social workers with the right tools to tackle community challenges.

### *b. Making Spaces for Community Voices*

Social work students have a role to play within their communities and the agencies that exist in it. One area where this can occur is within the social work student field placement by creating opportunities for students to have field placements in community practice settings where they can learn to do research and advocacy. Through engaging in community practice field education, social workers can learn how to elevate and center the voices of the communities that they are working with, as opposed to only using them for consultations. As discussed in Greene and Chambers' (2011) article, social work field placements are great opportunities for students to integrate CBR principles as well as to learn about systemic and structural oppression from the communities that experience them first hand. Field placements also allow social work students to understand the many steps involved in social change efforts and gain a better understanding of community engagement practices (Green & Chambers, 2011).

#### i. *Learning how to do Community-Based Research*

There are inherent challenges in ensuring that community voices are not only heard but are included and present at the forefront of any community initiative. Traditionally marginalized voices, such as those of QTPOC, are usually either drowned out by those with more power and privilege or are not sought out at all and are pushed even further into the margins of society. Moreover, marginalized communities can often be difficult to access due to their distrust of outsiders (Van der Meulen, 2001). In research, CBR is unique in a way that it seeks to engage in meaningful partnerships with the communities it is involved in, but even within a CBR framework, there are challenges to gaining and maintaining trust, especially with communities that have many complex and nuanced needs (Pinto, McKay, & Escobar, 2008). The controversy behind engaging marginalized communities is that they are often the ones who need to be included the *most* in community initiatives and projects and will usually benefit the most as well. Therefore, it is of utmost importance to ensure that marginalized community voices are centered in research, community initiatives, collaborations, city hall policy discussions, and more. Social work students involved in CBR projects in their field placements allows them numerous opportunities to learn of the community's needs first-hand and work towards finding solutions to challenges together.

### ii. *Advocacy*

Wertheimer et al (2004) remind us that social work ought to be deeply involved in policy and advocacy, yet that is something that is not heavily focused on in social work education and practice. Advocacy is described by Strier (2013) as being an umbrella concept that encompasses many definitions, such as elevating the voices of marginalized communities, engaging in joint actions towards policy change, and encouraging communities to take center stage when communicating their needs. However, social workers and students involved in advocacy ought to be cautious not to take on a leadership role, but instead to use their privilege and status for tasks such as mobilizing resources, bringing networks of people together, and setting up meetings with policy makers (Strier, 2013). As such, being involved in advocacy work ought to be required of all social workers in the field since it can help elevate the voices of those living on the margins of society.

## 3. Implications for Community-Based Research: CBR

Emerging from my reflections on my CBR process, are implications for CBR that occurs within a time limited, student engaged, social work research project. These include implications for community participation, attending to insider/outsider status, emotional labour and attending to issues of power and control.

### *a. Participation*

CBR practice lies on a wide research spectrum ranging from minimal community engagement to having community engaged at every step of the research process, as opposed to having strict black and white rules as to how to perform it (Israel, Schulz, Parker, & Becker, 1998). I attempted to keep this in mind through the duration of the research with the understanding that there exists a continuum of participation that is reflected in various CBR projects.

Thinking and reflecting about what constitutes participation is a unique tension that is ever-present in CBR research, especially since meaningful participation is a core

CBR principle (Arieli & Friedman, 2009). A big question that came up for me throughout the research was how to ensure the participants were not accidentally being tokenized because of their experiences. According to Travers et al. (2013), tokenism can be a potential side effect of figuring out the depth and amount of participation of community members in a research project. Throughout the project, I had to make sure that I was not bringing in the participants' voices or drawing on their experiences because I needed there to be a particular type of experience included in the research, but because that experience is valuable in and of itself. I constantly had to ask myself why I was pulling on a specific individual's experience, starting from the consultations all the way towards the data analysis process. While there is no procedure to follow to make sure tokenism is being avoided, an important implication that has emerged through my experience and reflections is to ensure that the research is transparent and authentic in its approach and in its relationships with the community. This can be a powerful tool in avoiding tokenistic words and actions because through being transparent with the community and with your research participants, you are also holding yourself accountable for how you frame their words and experiences. In my own experience throughout this research, my transparency with the participants held me accountable to ensuring their stories were being shared as they intended them to be.

### *b. Insider-Outsider Tension*

According to Van der Meulen (2011), insider research is when the research is largely led and conducted by a member of the community being studied, whereas outsider research is when the research is led by someone who does not identify with or have experiences related to the community and the research questions. It is of no surprise that marginalized communities would be wary of outsider researchers, because of the potential for exploitative research methods, poorly communicated motives, and just a general lack of trust (Benoit, C., Jansson, M., Millar, A., & Philips, R., 2005; Bournot-Trites, M., & Belanger, 2005). As a person living at the intersections of queerness and racialization, I too would be cautious and suspicious of non-queer and/or non-racialized researchers wanting to study the experiences of people like myself. The majority of the participants I worked with identified as queer themselves, making me an insider with this specific part of their identities. However, the majority, if not all, of the participants were living in a rural setting, which in turn makes me an outsider since I live in an urban city.

My insider-outsider status resulted in tensions that I experienced throughout the research process. These tensions were difficult to grapple with because, on one side, I felt like I could relate to the participants because of our shared LGBTQ2S+ identity, but on another side, I was struggling because I did not live in their community and thus did not experience their specific struggles. This made for interesting reflections to ensure that I was not overstepping where I did not understand, but also not hesitating to connect when an issue came up that I related with. An implication for those who traverse the insider-outsider tension on this personal level is to be mindful and in tune with one's place in the research while remembering that the researcher should not be the centre of the study and thus does not need to understand and relate to the participants' experiences at all times.

Akin to the insider-outsider tension, the personal-professional divide is another dynamic that often tags along that I have needed to manage and think through cautiously. A question that has come up in this research is: how do I, as the 'head researcher' who shares commonalities with the participants I am working with, separate the personal from the professional? As an insider, I have come to form close relationships with some of the participants because we share commonalities, but it is sometimes difficult to navigate scenarios when our day-to-day lives get entangled in the work. This tension, in my opinion, comes from feeling like I am expected to be wearing the 'researcher hat' at all times, as opposed to assessing the situation accordingly. Because academic research is expected to be 'professional', it is necessary for researchers to reflect on the alienating nature of this professionalism and work towards dismantling it. I believe it is beneficial for researchers to reassess what it means to be a professional, particularly when engaging with communities who do not engage with academia. Through reflecting on the very concept of professionalism, I believe we are able to better our practice as researchers and social workers because we are taking our contexts into consideration, as opposed to settling for what is expected of us.

### *c. Emotional Labour*

According to Mancini and Lawson (2009), emotional labour is described as managing one's feelings during paid employment so as to conform to professional rules. Wilkins (1993) situates this within an academic setting, stating that she rejects the notion that emotions, intuition, and human relationships ought to be covered up and sacrificed under the guise of intellectual and academic knowledge. I have come to find emotional labour to be a difficult topic to think about in this research because it brought forth some complicated feelings about who I am and what my role is in this research, thus making it an important concept to deconstruct and reflect on.

In both the consultations and the focus groups, I was not anticipating having to control my reactions as much as I did; the difficult stories that were being shared elicited neutral reactions from them at best, and frustrated eyerolls at worst, but my reactions felt much bigger. As a transparent person, the emotions I was experiencing were clearly marked in my body language, but the participants' reactions were surprisingly calm. It would not be a stretch to say that they have grown accustomed to these stories and blatantly become numbed towards them, but that is something that is troubling to me as a researcher trying to be as ethically aware as possible: is it my ethical responsibility to mirror their reactions, and thus mirror the emotional labour that they have put in? Is my lack of emotional regulation impacting them negatively?

I relate to this by thinking about my own experiences as the child of survivors of war. I often tell friends tales of my parents surviving shootings and bombings in their youth. I have normalized these experiences and thus show minimal emotions while reciting them, but the reactions I get from others are those of shock and horror, which in turn make me think: is there something wrong with me for not reacting like that? Is that how I am supposed to react? However, I can also think of the times when my friends' reactions to those stories were validating and provided me with a different perspective on experiences that I had set aside in my mind. Thinking about this experience makes it easier for me to place myself in the participants' shoes, but that does not mean that I can speak to what would make them comfortable. I also do not think this is something I could bring up as a topic of conversation, as I think it would be considered something along the lines of 'micromanaging'. Regulating emotions is an ethical tension that I have no answers to but is something that is worth thinking about and considering throughout the research process. One method that I utilized in order to better understand this ethical tension is debriefing with classmates who were experiencing a similar dilemma. Through sharing our experiences, we were better able to reflect on them and deconstruct them together.

### *d. Power and Control*

Another tension that emerged in my research process was in regard to issues of power and control. More specifically, I wanted to make sure that the participants had enough power and control within the research to steer it in whatever direction they felt it needed to go in. It was a difficult road to navigate because, while I wanted them to steer the research, they were looking towards *me* to tell them what I needed from them. Throughout the process, I did not want to unintentionally take away power from them by making decisions on their behalf; Traver et al (2013) coin this as unintentional disempowerment. Echoing Travers et al (2013), I was concerned with not being able to capitalize on some of the participants' skills and knowledge due to time pressures, budgetary restraints, or not being able to involve them in the more 'high-level' stages of research (Travers et al, 2013). This is an important issue to pay attention to as it ties in closely with the participants' capacity for participation, but also raises salient questions around potential exploitation.

The concept of unintentional disempowerment is one that I grappled with constantly because walking the line between "capitalizing on participants' strengths" and "exploiting participants' knowledge" is fraught with difficulty. Even though I want the participants to be involved in the research every step of the way, how could I ask already-exhausted participants to participate to that capacity, without even getting monetary compensation? Thinking through the outcomes of any project is a difficult but necessary process, since results are never guaranteed, despite one's best efforts. Ball (2014) introduces a controversial concept regarding informing the community of what they will get out of the research when it is complete, when the reality is that research inherently has unknown outcomes. The question that came out of Travers et al.'s (2013) discussion around unintentional disempowerment is: "how can we design community roles where all people on the team can really contribute their strengths?" (Travers *et al.*, 2013, p. 413). My personal addition to this question would be surrounding ethical compensation of the participants' labour. While monetary compensation was not built into the capacity of this research, honorariums were given to the participants as a show of respect for their knowledge and labour.

Another implication that I would highly encourage researchers to include in their research with communities is the creation of a Memorandum of Understanding (MOU). According to Guta et al (2010), an MOU is akin to a terms of reference document that outlines roles and responsibilities of all the members of the study, and to outline how the research team expects to address potential conflicts.

## 4. Implications for Healthcare Practitioners

The vast majority of the literature relating to LGBTQ2S+ sexual health has discussed capacity building for healthcare practitioners, which is also a finding that has come out of this research. Healthcare practitioners need better training, supports, and resources around LGBTQ2S+ sexual health in order to better serve the community (Campbell, 2013; Hsieh & Ruther, 2017; Keuroghlain, Ard, & Makadon, 2017; Lim, Brown Jr, & Sung Min, 2014; Scheim & Travers, 2017). There is also a push in the literature for LGBTQ2S+ people themselves to identify what cultural competence looks like for healthcare providers who are providing them with care, explaining that LGBTQ2S+ communities' experiences ought to set the context and define the issues at hand (Hsieh and Ruther, 2017; Travers et al, 2017).

Another large gap that needs to be addressed is that concerned with language, as the literature and this research have shown. In Carrotte et al's (2016) research, the authors found that language was a major component in how included and validated their participants felt, specifically the language around conflating gender and sex. Interestingly enough, Scheim and Travers (2017) found that even when healthcare practitioners were validating with the language that they used, their actions sometimes negated that effort and made the environment unsafe for trans MSM. This speaks magnitudes about the need for language, intentions, and actions to be aligned and geared towards ensuring LGBTQ2S+ individuals feel comfortable and safe accessing sexual health services. This applies to healthcare practitioners, frontline workers, nurses, and anyone else who may come in contact with LGBTQ2S+ individuals within a healthcare setting. Healthcare professionals need to be not only encouraged to attend capacity building workshops around LGBTQ2S+ health, but it instead needs to be part of their mandatory training to ensure that they are knowledgeable enough to provide care for LGBTQ2S+ populations.

# Chapter 6: Limitations of the Research

While the two focus groups that were held had both service providers and community members in dual roles, it would have been beneficial to have another focus group comprised of community members who do not work within a healthcare or social service context. This would have been helpful in shaping the context of sexual healthcare in the community and would have provided a different perspective of what the barriers looked like. Alas, due to the time restrictions of this study, as well as the difficulties in reaching LGBTQ2S+ individuals in a rural setting, that was not possible. It was also challenging to include a wide array of intersectional identities given the main pool of participants was from specific collaboratives that I was working with. While some of the participants belonged to historically marginalized communities, there were not nearly enough QTPOC voices in the room to be able to talk about those particular experiences. More time would need to be allotted in future research for getting to know the community in depth and to connect with different community pockets.

Due to the nature of focus groups, a few people were unable to participate at the times that were scheduled since the times that worked with the largest amount of people were chosen. It was difficult trying to accommodate the schedules of so many busy individuals, alongside my own schedule, making it inevitable to miss a few individuals along the way. While one-on-one interviews could have fixed the scheduling issue, I believe it would have severely limited the depth and breadth of the data that would have been generated since the richest data came from participants talking to each other as opposed to me asking them questions.

According to Jackson (2008), it could be helpful for CBR projects to engage community members in the data analysis process as well as the usual data collection. Undergoing a participatory data analysis process collectively with the participants could provide different interpretations of the data that academic researchers may miss (Jackson, 2008). While including the participants of this research in the data analysis process would have been extremely beneficial, it simply was not possible due to time restrictions, schedule conflicts, and lack of funds to compensate for labour.

Due to the time restrictions of this study, an MOU was not possible to create with members of the Collaborative. I believe this research could have benefited from having an MOU outlined that described how conflicts would have been responded to, but unfortunately, it was outside of the scope of this research.

## Concluding Remarks

Knowing all that we know about LGBTQ2S+ sexual health and how important it is to receive appropriate and timely medical care and information, we can conclude that it is a service that ought to be prioritized and not just left for the privileged and able. Because we know serious complications could arise from neglected sexual health, it would make sense to make access to sexual health services as barrier-free as possible. Issues such as heteronormativity, queerphobia, and transphobia make it increasingly more challenging for LGBTQ2S+ individuals to feel safe seeking care, while misinformed healthcare providers reinforce the sexual stigma that often follows LGBTQ2S+ individuals around. This research heavily focused on barriers to sexual health services, such as systemic red tape, the lack of confidentiality and transportation, and the difficulties of accessing out-of-town services. The creation of the single-point-of-contact service provider was also a phenomenon that surfaced in this research, bringing forth issues of burn out, tapered services, and thinning referrals.

However, no story would be complete without also highlighting the ways in which communities are resisting and pushing back against the barriers that they experience through strategies like collaboratives, grassroots services, and informal networks. While this research is not ground-breaking by any means, it does help shed light on an issue that may not seem like it would be of much importance, yet it is. Access to adequate and safe sexual health is not a stand-alone matter but is interconnected to the larger healthcare system at play, and even larger to society. LGBTQ2S+ individuals deserve to be treated with dignity and respect, regardless of what service they are accessing and regardless of where they reside.

# References

Alencar Albuquerque, G., Lima Garcia, C., Silva Quirino, G., Henrique Alves, M.J., Belem, J.M., Santos Figueiredo, F.W., Silva Paiva, L., Nascimento, V.B., Silva Maciel, E., Engracia Valenti, V., Abreu, L.C., & Adami, F. (2016). Access to health services by lesbian, gay, bisexual, and transgender persons: systematic literature review. *BMC International Health and Human Rights*, 16 (2).

Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., Holland, T., Holmes, C., Lee, A., McNulty, A., Moore, N., Nayling, N., Stokoe, A. & *Strachan, A. (2013). Everyday ethics in community-based participatory research. Contemporary Social Science*, 8 (3), 263-277.

Begun, A.L., Berger, L.K., Otto-Salaj, L.L., & Rose, S.J. (2010). Developing effective social work university-community research collaborations. *Social Work,* 55 (1), 54-62.

Benoit, C., Jansson, M., Millar, A., & Philips, R. (2005). Community-academic research on hard-to-reach populations: Benefits and challenges. *Qualitative Health Research, 15 (2), 263–282***.**

Brogaard, T., Jensen, A.B.,Sokolowski, I., Olesen, F., & Asbjørn Neergaard, M. (2011). Who is the key worker in palliative home care? *Scandinavian Journal of Primary Health Care*, 29 (3), 150-156.

Campbell, S. (2013). Sexual health needs and the LGBT community. Nursing Standard, 27 (32), 35-38.

Capper, C.A. (1998). Critically oriented and postmodern perspectives: sorting out the differences and applications for practice. *Educational Administration Quarterly*, 34 (3), 354-379.

Carrotte, E.R., Vella, A.M., Bowring, A.L., Douglass, C., Hellard, M.E., & Lim, M.S.C. (2016). "I am yet to encounter any survey that actually reflects my life": a *qualitative study of inclusivity in sexual health research. BMC Medical Research Methodology,* 16 (86).

Carter, S. M., & Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research*, 17 (10), 1316-1328.

Christopher S., Watts, V., McCormick, A., & Young, S (2007). Building and Maintaining Trust in a Community Based Participatory Research Partnership. *American Journal of Public Health*, 98 (8), 1398-1406.

DeHart-Davis, L., & Pandey, S.K. (2005). Red tape and public employees: Does perceived rule dysfunction alienate managers? *Journal of Public Administration Research and Theory,* 15 (1), 133-148.

DiCenso, A., Borthwick, V.W., Busca, C.A., Creatura, C., Holmes, J.A., Kalagian, W.F., & Partington, B.M. (2001). Completing the picture: adolescents talk about what's missing in sexual health services. *Canadian Journal of Public Health,* 92 (1), 35-38**.**

Dobrin, L.M., & Schwartz, S. (2016). Collaboration or participant observation? Rethinking models of 'linguistic social work'. *Language Documentation &*

*Conservation*, 10, 253-277.

Freeman, M. & Vasconcelos E. (2010). Critical Social Theory: Core Concepts, Inherent Tensions. *New Directions in Evaluation* 127, 7-19.

Garro, J. (2009, February 16). Canada's healthcare system is homophobic, says group. *Daily Xtra. Retrieved from* https://www.dailyxtra.com/canadas-healthcare-system-is-homophobic-says-group-37077

Gottschalk. L. (2007). *Coping with stigma: coming out and living as lesbians and gay men in regional and rural areas in the context of problems of rural confidentiality and social exclusion.* Retrieved from Research Gate. https://bit.ly/2MoNGu6

Ghabrial, M.A. & Ross, L.E. (2018). Representation and erasure of bisexual people of color: a content analysis of quantitative bisexual mental health research. *Psychology of Sexual Orientation and Gender Diversity*, 5 (2), 132-142.

Greene, S., Ahluwalia, A., Watson, J., Tucker, R., Rourke, S.B., Koornstra, J., Sobota, M., Monette, L., Byers, S. (2009). Between Skepticism and Empowerment: The Experiences of Peer Research Assistants in HIV/AIDS, Housing and Homelessness Community-Based Research. *International Journal of Social Research Methodology,* 12(4): 361-373.

Greene, S. and Chambers, L. (2011). The Community-Based Research Practicum as Anti-Oppressive Social Work Education in, D. Baines (Ed), *Doing Anti-Oppressive Practice, 2nd edition, Blackpoint, NS: Fernwood Publishing, 162-175.*

Greene, S. (2013). Peer Research Assistantships and the Ethics of Reciprocity in

Community-based Participatory Research. *Journal of Empirical Research on Human Research Ethics*. 8 (2), 141-152.

Hall, B. (2014). Learning to listen: foundations of teaching and facilitating of participatory and community-based research. In Etmanski, C., Hall, B.L. *& Dawson, T. (Ed). Learning and teaching community-based research: linking pedagogy to practice* (150-164). Toronto: University of Toronto Press.

Hammer, B., Fletcher, F., & Hibbert, A. (2017). Participant observation: enhancing the impact measurement in community based participatory research. *The Qualitative Report*, 22 (2), 439-455.

Higginson, A. (2012). *The Durham Region Health SexYouthality Project: youth's perspectives of sexual health needs in Durham region. Retrieved from* University of Ontario: Institute of Technology. Electronic Theses and Dissertations, Masters Thesis. http://hdl.handle.net/10155/250

Hsieh, N., & Ruther, M. (2017). Despite increased insurance coverage, nonwhite sexual minorities still experience disparities in access to care. *Health Affairs*, *36* (10), 1786-1794.

Hubach, R.D., Currin, J.M., Sanders, C.A., Durham, A.R., Kavanaugh, K.E., Wheeler, D.L., & Croff, J.M. (2017). Barriers to access and adoption of pre-exposure prophylaxis for the prevention of HIV among men who have sex with men (MSM) in a relatively rural state. *AIDS Education and Prevention*, 29 (4), 315-329.

Hubach, R.D., Dodge, B., Schick, V., Ramos, W.D., Herbenick, D., Li, M.J., Cola, T., & Reece, M. (2015). Experiences of HIV-positive gay, bisexual, and other men who *have sex with men residing in relatively rural areas. Culture, Health & Sexuality*, 17 (7), 795-809.

Hunt., R, & Fish, J. (2008) *Prescription for Change: Lesbian and Bisexual Women's Health Check, 2008. Stonewall. Retrieved from* **www.stonewall.org.uk/lesbianhealth**

Israel BA, Schultz AJ, Parker EA, & Becker AB (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19173- 202.

Jackson, S.F. (2008). A participatory group process to analyze qualitative data. *Progress in Community Health Partnerships: Research, Education, and Action. 2 (2),* 161-170.

Jackson, B., Daley, A., Moore, D., Mulé, N. J., Ross, L.E., & Travers, A. (2006, January). An intersectional approach to sexual orientation, gender identity and the development of public health goals for Canada. *Whose Public Health?* Rainbow Health Ontario. Retrieved from https://www.rainbowhealthontario.ca/resources/whose-public-health-an-intersectional-approach-to-sexual-orientation-gender-identity-and-the development-of-public-health -goals-for-canada/

Kazyak, E. (2011). Disrupting cultural selves: constructing gay and lesbian identities in rural locales. *Qualitative Sociology*, 34 (4), 561-581.

Keuroghlian, A.S., Ard, K.L., & Makadon, H.J. (2017). Advancing health equity for lesbian, gay, bisexual and transgender (LGBT) people through sexual health education and LGBT- affirming health care environments. *Sexual Health*, 14, 119-122.

King, S., & Dabelko-Schoeny, H. (2009). "Quite frankly, I have doubts about remaining": Aging-in-place and health care access for rural midlife and older lesbian, gay, and bisexual individuals. *Journal of LGBT Health Research*, 5, 10-21.

Kitzinger, J. (1995). Qualitative research. Introducing focus groups. *British Medical Journal*, 311 (7000), 299.

Lim, F.A., Brown Jr, D.V., & Sung Min, J.K. (2014). Addressing health care disparities in the lesbian, gay, bisexual, and transgender population: a review of best practices. *American Journal of Nursing, 114* (6), 24- 34.

Maiter, S., Joseph, A., Shan, N., & Saeid, A. (2013). Doing participatory qualitative research: Development of a shared critical consciousness with racial minority research advisory group members. *Qualitative Research*, 13(2), 198-213.

Maiter, S., Simich, L, Jacobson, N, & Wise, N. (2008). Reciprocity: an ethic for community-based participatory *Action Research,* 6(3), 305-325.

Mancini, M. & Lawson, H. (2009). Facilitating positive emotional labor in peer-providers of mental health services. *Administration in Social Work*, 33, 3–22.

Mason, J. (2002). *Qualitative Researching,* 2nd Edition. London: Sage Publications.

Mulé, N. J., Ross, L.E., Deeprose, B., Jackson, B.E., Daley, A., Travers, A., & Moore, D. (2009). Promoting LGBT health and wellbeing through inclusive policy development. *International Journal for Equity in Health*, 8 (18).

Mulé, N. J. (2005). Beyond words in health and well-being policy. *Canadian Review of Social Policy, 55, 79-98.*

Mulé, N. J., & Smith, M. (2014). Invisible populations: LGBTQ people and federal health policy in Canada. *Canadian Public Administration*, 57(2), 234–255.

Muscolino, R. (2016). Breaking the awkward barrier with #ComePrEPd: A community-led HIV prevention campaign [online]. HIV Australia, 14 (2), 38-41.

Neely, E., Walton, M., & Stephens, C. (2016) Fostering social relationships through food rituals in a New Zealand school, *Health Education,* 116 (5), 434-448.

Neuman, L. (1997). The Meanings of Methodology. In Neuman, W.L. Social Research Methods: Qualitative and Quantitative Approaches (pg. 43-66). Boston, Mass.: Allyn & Bacon.

Nowell, L.S., Norris, J.M., White, D.E., & Moules, N.J. (2017). Thematic analysis: striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16, 1-13.

Parr, S. (2016). Conceptualising 'the relationship' in intensive key worker support as a therapeutic medium. *Journal of Social Work Practice*, 3 (1), 25-42.

Pinto, R.M., McKay, M.M., & Escobar, C. (2008). "You've gotta know the community": Minority Women Make Recommendations About Community-Focused Health Research. *Women and Health*, 47(1), 83-104.

Power, J., McNair, R., & Carr, S. (2009) Absent sexual scripts: lesbian and bisexual women's knowledge, attitudes and action regarding safer sex and sexual health information. *Culture, Health & Sexuality*, 11 (1), 67-81.

Ryan, G.T. & Bernard, H.R. (2003). Techniques to Identify Themes. *Field Methods* 15(1), 85-109.

Scheim, A.I., & Travers, R. (2017). Barriers and facilitators to HIV and sexually transmitted infections testing for gay, bisexual, and other transgender men who have sex with men. *AIDS Care*, 29 (8), 990-995.

Schnarch, B. (2004). Ownership, control, access and possession: (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health*, 80-95.

Strand, K., Marullo, S., Cutforth, N., Stoecker, R., & Donohue, P. (2003). Principles of best practice for community-based research. *Michigan Journal of Community Service Learning*, 5-15.

Strier, R. (2013). Responding to the global economic crisis: Inclusive social work practice. *Social Work*, 58 (4), 344-353.

Travers, R., Pyne, J., Bauer, G., Munro, L., Giambrone, B., Hammond, R., & Scanlon, K. (2013). 'Community Control' in CBPR: Challenges experienced and questions raised from the Trans PULSE Project. 11(4), 403-422.

Travers, R., Wilson, M., Flicker, S., Guta, A., Bereket, T., McKay,C., Van der Muelen, A., Cleverly, S., Dickie, M., Globerman, J., & Rourk, S.B. (2008). The Greater

Involvement of People living with AIDS Principle: Theory vs. Practice in Ontario's HIV/AIDS Community-Based Research Sector. *AIDS Care*, 20(6), 615-624.

Van der Meulen, E. (2011). Action Research with Sex Workers: Dismantling Barriers and Building Bridges. *Action Research*, 9(4), 370-384.

Warr, D., Mann, R., & Tacticos, T. (2011). Using peer interviewing methods to explore place-based disadvantage: Dissolving the distance between suits and civilians. *International Journal of Social Research Methodology*, 14(5), 337–352.

Wertheimer, M.R., Beck, E.L., Brooks, F., & Wolk, J.L. (2004). Community partnerships: An innovative model of social work education and practice. *Journal of Community Practice, 12 (3-4), 123-140.*

Wilkins, R. (1993). Taking it personally: A note on emotion and autobiography. *Sociology*, 27(1), 93–100.

Williamson, I.R. (2000). Internalized homophobia and health issues affecting lesbians and gay men. *Health Education Research*, 15 (1), 97-107.

Wolfinger, N.H. (2002). On writing fieldnotes: collection strategies and background expectancies. *Qualitative Research,* 2 (1), 85-95.

Zahle, J. (2017). Privacy, informed consent, and participant observation. *Perspectives on Science,* 25 (4), 465-487.

# Appendices

## Appendix A: Email-Verbal Recruitment Script

Hello (name),

My name is Rasha Taha and I am a Masters of Social Work student at McMaster University. I am working in partnership with the AIDS Network (TAN) on their evaluation of service accessibility in Brantford. As part of this process, Jamie Dereniowski, the regional worker for TAN, is inviting you to participate in our collaborative project.

Our goal is to learn about the sexual health services that are available to LGBTQ+ individuals in Brantford, and how accessible, available, and appropriate they are for this particular population. We are also interested in learning about the gaps and barriers that exist within and between these services so that we can work towards potential solutions.

If you are interested in participating or have any questions regarding the research, please feel free to contact me by email.

Kindest regards,

Rasha Taha

## Appendix B: Letter of Information & Consent

DATE: ________

## LETTER OF INFORMATION / CONSENT

### A Study about Sexual Health Service Access for LGBTQ2S+ Individuals Residing in a Rural Canadian Community

| **Supervisor:** | **Student Investigator:** |
|---|---|
| Dr. Saara Greene | Rasha Taha |
| School of Social Work | School of Social Work |
| McMaster University | McMaster University |
| Hamilton, ON, Canada | Hamilton, ON, Canada |
| (905) 525-9140 ext. 23782 | (905) 525-9140 |
| E-mail: greenes@mcmaster.ca | E-mail: tahar2@mcmaster.ca |

**What are we trying to learn through this study?**

You are invited to take part in this study on sexual health accessibility for the LGBTQ2S+ population in Brantford. We are interested in learning how accessible and appropriate sexual health services in Brantford are for LGBTQ2S+ (lesbian, gay, bisexual, transgender, queer, two-spirit) individuals because we know that this population is at a higher risk of contracting sexually transmitted diseases, including HIV. We hope to learn about what kind of gaps and barriers exist so that we can try to find ways of solving them.

I am doing this study in collaboration with the AIDS Network in Hamilton in the form of a community-based research project. I am doing this research for my Masters of Social Work thesis.

This is a line of research that I hope to continue in the future and will use parts of the emerging data from this project for future related studies.

## What will happen during this study?

I will be facilitating a focus group with service providers and community organizers who attend the Bridge Brant meetings. This includes asking the participants to simultaneously discuss the sexual health services that they know about in their community and how an LGBTQ2S+ individual would go about navigating these services.

I will ask you to collectively discuss what sexual health services look like in Brantford based on your knowledge and expertise. The focus will be on LGBTQ2S+ individuals, so I will make sure we discuss the specifics of that community.

I will be relying on the knowledge around the room to guide this process, so I encourage you to add questions and comments that are outside of the interview guide.

The session will last about one and a half (1.5) hours, and we can schedule another meeting as well if we need more time. If you would prefer to have a one-on-one interview instead, that option is available. Prior to conducting the focus group, I will go through the consent form with everyone, and after everyone has signed it, we can begin. With your permission, I will have an audio recorder there so I do not miss important information.

## Are there any risks to doing this study?

The risks involved in participating in this study are minimal. You might experience risks that are psychological in nature. You may feel anxious, upset, or uncomfortable with the material that is discussed in the group. You may get overwhelmed that the problems may look insurmountable, and that could lead you to feel uneasy.

You may also experience social risks since you could express views that others may not share and thus feel uncomfortable amongst your professional peers. You may also worry about how others will react to what you say.

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. I describe below the steps I am taking to protect your privacy.

If you feel like you need to debrief with someone about how you are feeling, I will be available after the session is over and would be happy to talk with you.

### \Are there any benefits to doing this study?

While there may not be any specific benefits to you personally in the short term, the goal is to obtain longer term benefits to LGBTQ2S+ individuals. Through developing a better understanding of barriers and facilitators to sexual health services in Brantford as an LGBTQ2S+ individual, the goal will be to develop a strategy that reflects the needs of these individuals.

The research could potentially benefit you through revealing the bigger picture of how systems interact with one another. You will also benefit from hearing other people's suggestions on how to bridge the gaps and barriers that people experience.

### Honorarium

You will be given a gift card in exchange for your participation in the study.

### Who will know what you said or did in the study?

You are participating in this study confidentially. I will not use your name or any of your information **other than your job title <u>or</u> preferred generic descriptor** that would allow you to be identified. No one but myself and my supervisor will know whether you were in the study unless you choose to tell them.

That being said, since the community is small, others may be able to identify you on the basis of references you make or through your style of speech. Please keep this in mind in deciding what to tell us. If you would rather not be directly quoted, please let me know and I will make sure I avoid doing so when disseminating the research results.

The information/data you provide will be kept in a locked desk where only myself and my supervisor will have access to it. Information kept on a computer will be protected by a password.

Once the study is complete, an archive of the data, without identifying information, will be maintained. That is so we can disseminate the information through brochures, pamphlets, or an infographic.

### Specifics of confidentiality in a focus group

- The information which we will collect today will be attributable *(connected or associated)* to you <u>as a group</u>, but *also* to your job title <u>or</u> preferred generic descriptor

- We *are* assuming that when we learn about one another's views, they remain confidential. In a small community (group) like this, people are identifiable to some degree by their views and opinions
- Having said this, and having made these requests, you know that we cannot guarantee that the request will be honoured by everyone in the room
- We are asking you to make only those comments that you would be comfortable making in a public setting; and to hold back making comments that you would not say publicly
- If you want to stop being in the focus group you can you can leave or stay and simply stop talking, but it will not be possible for you to pull out your data from the flow of the conversation because of the interconnected nature of the group discussion where one person's comments can stimulate the sharing of comments made by others in the group
- Anything heard in the room should stay in the room
- All voices are to be heard, so I will step in if too many people are speaking at once or to make sure that everyone has a chance to speak
- I may also step in if I feel the conversation is straying off topic

**What if you change my mind about being in the study?**

Your participation in this study is voluntary. If you decide to be part of the study, you can stop participating for whatever reason, even after signing the consent form or part-way through the study up until July 30th, 2018, when I expect to be submitting my thesis.

If you want to stop being in the focus group you can stay and simply stop talking or you can leave, but it will not be possible for you to pull out your data from the flow of the conversation because of the interconnected nature of this type of group discussion where a person's comments can stimulate the sharing of comments made by others in the group.

**How do you find out what was learned in this study?**

I expect to have this study completed by August 2018. If you would like a summary of the results, please let me know how you would like it sent to you. It may either be a one-page summary or it could be in the form of an infographic.

☐ Yes, I would like to receive a summary of the results. You can send it to

----------------------------------------------------------

☐ No, I would not like a summary of the results.

**Questions about the Study**

If you have questions or need more information about the study itself, please contact me at:

tahar2@mcmaster.ca
**or**
rashataha7@gmail.com

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

C/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

**CONSENT**

- I have read the information presented in the information letter about a study being conducted by Rasha Taha, of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time or up until July 30th, 2018.
- I have been given a copy of this form.
- I agree to participate in the study.

Signature: ______________________ Date: _________________________

Name of Participant (Printed) ___________________________________

1. I agree that the interview/focus group can be audio [video] recorded.

[ ] Yes

[ ] No

2. I agree to have my responses from this project used in future related projects.

[ ] Yes

[ ] No

3. [ ] Yes, I would like to receive a summary of the study's results.

Please send them to me at this email address

______________________________________

Or to this mailing address:

_____________________________________________________

[ ] No, I do not want to receive a summary of the study's results.

4. I agree to be contacted about a follow-up interview, and understand that I can always decline the request.

[ ] Yes, please contact me at:

__________________________________________________

[ ] No

## Appendix C: Semi-Structured Interview Guide

## A Study about Sexual Health Service Access for LGBTQ2S+ Individuals Residing in a Rural Canadian Community

**Researcher**: Rasha Taha

### I) Introduction and Instructions

Hello, my name is Rasha. Thank you for agreeing to participate in this focus group meeting. Just to remind everyone, I'm looking to map out how LGBTQ+ individuals living in Brantford navigate sexual health services to see how accessible and available these services are; the hope is to be able to bridge any barriers or gaps that come up in the findings.

**What is a focus group?** A focus group is an interactive group discussion where we can gain several perspectives about a topic and members of the group can think about and comment on what others have said in the group.

**What will you be doing?** You will be participating in an arts-based mapping process that will allow us to see the bigger picture of what sexual health service access looks like in Brantford. We have a big sheet of paper and some markers for your use. Given each of you is knowledgeable about certain pieces of the puzzle, the aim here is for everyone to cooperate to be able to come as close as possible to a full picture. While you are participating, I would encourage you to speak about what you are adding to the map and why you are doing so.

Just as a reminder, there are snacks and refreshments, so please help yourself at any point. In a minute, we will all introduce ourselves – first names and/or job titles only. But first, I would like to walk you through the consent form that is in front of you.

### Confidentiality

Before we begin our discussion, I want to spend a few moments talking about confidentiality and to go over some basic ground rules for our focus group discussion today:

- Everyone's views are welcomed and important.
- The information which we will collect today will be attributable *(connected or associated)* to you as a group, but *also* to your job title *or to a generic descriptor of your choice*
- We *are* assuming that when we learn about one another's views, they remain confidential. In a small community (group) like this, people are identifiable to some degree by their views and opinions.
- Having said this, and having made these requests, you know that we cannot guarantee that the request will be honoured by everyone in the room.
- We are asking you to make only those comments that you would be comfortable making in a public setting; and to hold back making comments that you would not say publicly.
- If you want to stop being in the focus group you can you can leave or stay and simply stop talking, but it will not be possible for you to pull out your data from the flow of the conversation because of the interconnected nature of the group discussion where one person's comments can stimulate the sharing of comments made by others in the group.
- Anything heard in the room should stay in the room.
- All voices are to be heard, so I will step in if too many people are speaking at once or to make sure that everyone has a chance to speak.
- I may also step in if I feel the conversation is straying off topic.
- You can expect this discussion group to last about one and a half (1.5) hours.

**Use of Tape Recorder**

- As you will recall, this focus/discussion group will be recorded to increase accuracy and to reduce the chance of misinterpreting what anyone says.
- All tapes and transcripts will be kept under lock and key by the researcher.
- Names will be removed from transcripts. Participants will have coded numbers along with their job titles attached to their name which only I will know.
- Only I and my supervisor will have access to transcripts (with your personal names removed) of this focus group.
- I'll also ask that when using abbreviations or acronyms, you say the full name at least once to aid transcription.

## II. Interview

- **Interview questions**

**<u>NB</u>:** Due to the nature of community-based research, this is a semi-structured interview guide, meaning that these questions are only meant to be a guide. Questions will change according to what participants have to say; more questions may also be added according to what the participants deem as important.

    - Where would an LGBTQ+ individual go to get tested*? (insert range of sexual health tests here)*
    - How accessible are these services? (By accessible, I mean are they safe for LGBTQ+ individuals to access without being harassed, discriminated against, or met with lack of knowledge and/or refusal of services) This can include competency with all members of the LGBTQ+ community (trans individuals included), as well as general acceptance of sexual and gender minority individuals.
    - If an LGBTQ+ individual wanted to get tested for HIV/hepatitis C, where would they go? Is there rapid testing available? At what sites? How would they receive results? Would they be able to receive required medicine at those sites? Would they have support with that process/their diagnosis?
    - If an individual were to test positive, where, how, and when would they be able to receive counseling on their treatment options?
    - Where would a teenage LGBTQ+ individual go for anonymous testing?
    - What kind of outreach/service promotion do agencies take part of?
    - How long does it take, roughly, for someone to obtain results of their diagnoses?
    - How physically accessible are these services in the community, as in, are they on a bus route? Or do people need to drive to access them?
- Is there anything we forgot or is there something important that we should know about before we wrap up?

## III. Wrap Up

- Just a general reminder, what was said in this room should stay in this room.
- If anyone needs support or would like to discuss something that has bothered them, myself or Jamie will be available afterwards.
- Thank you for your participation!