

POLICY IN MOTION: LGBTQ+ HEALTH FROM THE FRINGES TO MAINSTREAM?

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Abstract

This manuscript-based dissertation examines the perceptions and experiences of selected community-based LGBTQ+ health organizations in the Greater Toronto and Hamilton Area of Ontario as they navigate the current neoliberal policy environment. It also examines how well these organizations understand and implement the social determinants of health (SDH) framework in their communities within that environment. As such, the SDH's structural approach to health equity, augmented by an emergent Queer Liberation Theory, forms the theoretical foundation of this analysis. For historical context, I conducted a content analysis of *The Body Politic's* coverage of the HIV/AIDS crisis from 1981 to 1987 to examine the impact of HIV/AIDS on the movement. I also conducted semi-structured interviews with people who were active with the publication during that period for their reflections on how the movement has developed. To understand the place of LGBTQ+ health in the existing policy environment, I collaborated with colleagues to analyze how LGBTQ+ health is represented on the Ontario Ministry of Health and Long-term Care's and the Ontario Local Health Integration Networks' websites. We conducted comparative "snapshot" content analyses in 2009 and 2017. To contextualize the comparative content analysis, we conducted semi-structured interviews with bureaucrats to see how well stated policies and commitments to health equity matched with real policy initiatives. With these insights, I conducted semi-structured interviews with staff of community-based LGBTQ+ health organizations to understand their perceptions and experiences of the policy environment and of the SDH approach more broadly. Findings indicate that LGBTQ+ health equity is a very small part of the policy discussion and remains very much on the fringes of health care policy and programming in any practical sense. LGBTQ+ organizations have a good understanding of equity issues and the SDH approach but must operate in "survival

mode.” The theoretical contribution of this work is to point out the inadequacy of the SDH framework’s understanding of LGBTQ+ health equity and to articulate three pillars in the development of Queer Liberation Theory (anti-assimilationism, solidarity across movements, and political economy) in the hope of improving the SDH framework and moving forward equitable approaches to LGBTQ+ health in a challenging policy environment.

Keywords: LGBTQ+, Health Policy, Queer Liberation Theory, Social Determinants of Health, Health Equity

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List of Abbreviations

ASOs	AIDS Service Organizations
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer + emerging sexualities and identities
LHINs	Local Health Integration Networks
MOHLTC	Ministry of Health and Long-term Care
MSM	Men who have sex with men
SDH	Social determinants of health
TBP	<i>The Body Politic</i> (chapter 3 only)

Chapter One: Introduction

When the “plague” of HIV/AIDS hit the gay community in the late twentieth century, the community responded—when no one else would. In a short period of about 10 years, an epidemic changed the landscape of gay activism. The remarkable and effective response from activists, reflected in this research through the pages of a leading Canadian publication, *The Body Politic*, was central to the development of the community’s identity and the gay liberation movement. Although HIV is now considered a manageable, chronic condition, its impact continues to influence how we think about health equity for the LGBTQ+ community. As the community continues to struggle and evolve, it has made an effort to more inclusive of its various components. As such, we now use the term LGBTQ+ to recognize and be open to diverse sexual orientations and gender and identity expression. Despite apparent gains for the LGBTQ+ community in Canada, including the taming of HIV/AIDS, I argue that health equity that we need to build on the liberationist perspective found in the pages of *The Body Politic* towards Queer Liberation.

This manuscript-based dissertation uses document analysis and semi-structured interviews analyzed through a critical, realist framework to a) understand the impact of the AIDS epidemic on the gay liberation movement of the 1970s and 1980s; b) situate LGBTQ+ health equity within the current policy arena in Ontario; c) illustrate the impact of neoliberal policies on the perceptions and experiences of selected community-based Queer health organizations; d) explore the possibility of an LGBTQ+ Health Strategy (either provincially or nationally); and e) reflect on the changes in the politics of the movement through the lens of Queer Liberation Theory. The findings of this research are presented in thematically connected but individual studies, presented in chapters 3, 4, and 5. Each of these manuscript chapters includes an abbreviated review of the

relevant literature, a description of the methods and theoretical frameworks used in the chapter, a presentation of the research findings, and by a discussion and conclusion. Each of the core manuscript chapters stands alone. Together, however, they offer a glimpse into the history of Queer health paradigms and activism, as well as some reflections on the current debates and activities.

This introductory chapter provides the outline and direction of the research, definitions that were used, and three literature reviews that provide the foundation for the briefer literature reviews in each manuscript chapter.

Research Questions

This dissertation grew out of a content analysis of the debates in *The Body Politic* publication during the period that AIDS first emerged in North America (1981-1987). This study included interviews with 10 gay and lesbian activists and contributors to the publication (McKenzie, 2016). I noted the vital influence that this publication had on the community's efforts to understand and react to the emergence of HIV/AIDS. *The Body Politic* publication was both a grassroots vehicle for activism, debate, and political change, and its own record of this defining social period of gay liberation. I was inspired by a gay liberation movement that was clearly centred on left-wing, socialist politics.

The gay liberation movement in the 1970s and 1980s seemed very different from my experience as a gay activist now. Current LGBTQ+ politics emphasizes individual rights and responsibilities: same-sex benefits, marriage equality, parenting rights, pride, and acceptance. In contrast, the politics of the early movement, at least as represented in *The Body Politic*, aligned more with my own structural analysis of liberation and equity for those who face oppression. I wanted to explore how and why this shift in focus from community-defined LGBTQ+ equity to

more individualized equality occurred, and what the movement has gained and lost through this evolution. In short, I wanted my dissertation to examine why we (the Queer community) no longer organize and conceptualize issues in the same structural way that I appreciated in *The Body Politic*.

To make this rather daunting task more manageable and coherent, I decided to study a few of the organizations to which the early movement gave life. Specifically, I wanted to understand how government funding for AIDS Service Organizations impacted the politics of the movement.

To undertake this research, I explored four related questions. These are fleshed out in subsequent chapters. First, I examined how the LGBTQ+ community made sense of and responded to the AIDS epidemic between 1981-1987. Second, with colleagues, I looked at how well LGBTQ+ health needs are currently represented by the Ontario Ministry of Health and Long-term Care and its regional administrative agencies, the Ontario Local Health Integration Networks. Furthermore, how well do policy-makers and funders understand health equity and do they properly address the health needs and social determinants of health (SDH) for the LGBTQ+ community? Third, I asked how the work of third sector LGBTQ+ organizations in the Greater Toronto and Hamilton Area both shapes and responds to current and evolving neoliberal funding policies

While engaging with these questions, I realized that there is no LGBTQ+ health strategy in Ontario or Canada. Thus, my fourth research question examined why this is the case and explores the merits and disadvantages of this idea with research participants.

Contribution to the Field

I feel this research makes both a theoretical and practical contribution to the field of health policy and equity, and LGBTQ+ health equity in particular. The theoretical contribution, specifically through the lens of Queer Liberation Theory, attempts to challenge current approaches to health equity that emphasize intersectionality, unique identities, and community development, especially if it stops short of fundamental structural change. This challenge does not negate the positive attributes of these approaches nor their contribution to our understanding and improvement of health inequities. Rather, my research attempts to hit the “reset” button on health equity theory to reboot a greater emphasis on political and economic factors in health. Although an SDH approach is well established for analyzing these factors in health, my research illuminates that the SDH framework does not adequately address sexual orientation and gender identity and expression as an SDH. More practically, this research identifies health equity issues regarding LGBTQ+ communities and promotes a discussion about a policy response and reflection on its implications.

Content of Each Chapter

Chapter 2 outlines the theoretical framework and overall methodology. Because each study uses a slightly different theoretical approach, Chapter 2 offers details about each theory used: social movement theory, the SDH framework, and Queer Liberation Theory.

Chapter 3 provides the historical context for my research. It demonstrates that the AIDS epidemic was a defining moment in the development of the North American gay social movement, as it confronted medical and governmental apathy while grappling with the realities of a deadly virus and the community’s need for “self-managed oppression.” (McKenzie, 2016)¹

¹ Chapter 3 is published in the *Journal of Homosexuality* with the title, “Love, lust, and loss in the early age of AIDS: The discourse in *The Body Politic* from 1981 to 1987” (McKenzie, 2016).

A content analysis of the debates in *The Body Politic* illustrate how the gay liberation movement responded to the AIDS crisis. Four key themes emerged: AIDS challenged the gay sexual culture; the community had to develop the concept of safer sex; the government response to the crisis was slow and inadequate; and AIDS raised complex issues related to diagnosis and disclosure. Ten in-depth interviews with prominent activists and contributors from the period helped to validate my textual analysis. This study contextualizes LGBTQ+ health and socio-political inequalities during a health crisis. The analysis of the shifting Canadian gay liberation movement inspired and helped inform my thinking and led me to consider Queer Liberation Theory for my research and for its potential impact for the community.

Chapter 4 examines how well contemporary LGBTQ+ health inequities are understood, both in the current policy environment and within the SDH framework itself. This chapter, titled “LGBTQ+ and Ontario’s Health Care Policies and Programs,” was written collaboratively with Nick Mulé and Maryam Khan. It involves a snapshot content analysis of the websites of the Ministry of Health and Long-term Care and each of Ontario’s 14 Local Health Integration Networks’ at selected points in time. These findings were also complemented by interviews with policy-makers. They are contextualized by a literature review of health inequities faced by the LGBTQ+ community and of the SDH literature and how it approaches sexual orientation and gender identity and expression, both discussed below.

Chapter 5 focuses on the current policy-making dynamics from the perspectives of both LGBTQ+ organizations and selected policy-makers/funders. It analyzes 20 semi-structured, in-depth interviews with community-based stakeholders, government funders. This chapter reflects on the issues raised in the literature on the impact of neoliberalism on third-sector community organizations, also discussed in detail below. Specifically, this literature identified concerns

about the impact of government policy on working conditions, possibilities for advocacy and activism, and professionalization and bureaucratization, especially as each of these manifests itself in demands for evidence-based practices and evaluation.

Chapter 6 summarizes the key findings of each of the studies and how they link together, including the impact of neoliberal policies on the work of these organizations and the community, the current state of understanding of structural determinants of health among the participants, and the important contributions these findings make to Queer Liberation Theory. I also concluded with how all of this contributes to our understanding of the risks and potential advantages of an LGBTQ+ Health Strategy.

Definitions and Terminology

This dissertation uses a number of terms in varied ways and contexts, as defined here. The “community” in question is defined as inclusive of all groups represented by the term Lesbian, Gay, Bisexual, Transsexual, Transgender, Queer (LGBTQ+) including Two-Spirited people. More conceptually, as Mulé (2012) points out, “the term “Queer” [allows for] a way of looking at the world through a lens that is decidedly not straight or traditionally...gendered” or fixed in any way (para 1). In other words, “Queer” encompasses any non-heteronormative expressions of sexual orientation and gender identity and expression (Mulé, 2016). “Queer” can also be understood as the political reclaiming of a pejorative label that has come to denote pride and celebration of a distinct culture, sometimes with political views that resist mainstreaming and assimilation (Brown, 2007; Mulé, 2016). “Queer” as an identifier and label can be either self-selected or imposed on a group or individual. For example, men who have sex with men (MSM) may choose to self-identify as straight if they are able to passably perform heterosexuality and if “being straight” helps maintain or secure a socioeconomic status or

personal safety. In other scenarios, it may be beneficial to identify as Queer to leverage a minority status. It is also important to point out that there will never be “universally accepted definitions of all the labels we have worn,” but that, more importantly, “a movement [like gay liberation and now Queer liberation] that eventually seeks to include all gay people cannot afford to try to reach such a consensus” (Bearchell, 1977, p. 11).

I use “cisgender” to refer to a person whose “biologically assigned sex at birth aligns with normative perceptions of gender,” (Mulé, 2016, p. 2), such as when an infant is born with female sex organs and grows up to identify with the female gender. “Heterosexism” is defined as the notion that heterosexuality is the normative and superior sexual identity (Mulé, 2016). Heterosexism emerges from the concept of heteronormativity, which places heterosexual sexual dynamics in a moral position of superiority and idealism (Oswald, Blume, Libby & Marks, 2005). The related term, “heteronormativity” is defined as the ideological, hegemonic basis for exclusory practices and policy such as the ongoing backlash to the 2015 update to the Ontario sexual health sections within the revised Kindergarten to grade 8 Health and Physical Education curriculum (McKenzie, 2015).

“Political economy” in this thesis refers to “...the study of social relations, particularly the power relations that mutually constitute the production, distribution, and consumption of resources” (Mosco, 1996, p. 25). Political economy considers the state, civil society, and individuals not as “independent variables”, but rather as inter-related parts of a whole (Armstrong, Armstrong, & Coburn, 2001). Furthermore, “Feminist Political Economy” considers the *gendered* nature of state, civil society, and economy, highlighting the role and relationship of social production to material production (Armstrong & Armstrong, 1983; Bakker, 2007; Smith, 1989; Vosko, 2002), and adding the household to the equation.

“Neoliberalism” is defined as the economic and political doctrine widely adopted in western capitalist nations starting in the 1970s, which emphasizes free markets and reducing the role of the state in business, as well as the role of the welfare state in social protection (Chernomas & Hudson, 2007; Harvey, 2009; Navarro, 2002). Although there is some debate about the decline of neoliberalism’s influence (O’Hara, 2010), my research observed its historical significance.

Though definitions of “health inequity,” can be elusive (Braveman, 2014), I follow Graham (2007) and Raphael (2011) and use the term to denote differences in health that are “structurally imposed and socially produced” (Graham, 2007, p. 36), thus rendering them “politically, socially, and economically unacceptable” (World Health Organization, 1978, para 3). Critical to my analysis is Braveman’s (2014) notion that a critical component of “health equity” is that it calls for mobilization and action.

Health equity is the principle underlying a commitment to reduce—and, ultimately, eliminate—disparities in health and its determinants, including social determinants. Pursuing health equity means striving for the highest possible standard of health for all people and giving special attention to the needs of those at greatest risk of poor health, based on social conditions (Bartley, 2009; Braveman, 2006; Shaw, Dorling, Gordon, & Smith, 1999). Thus, the SDH framework is closely linked to notions of “health inequity”. This framework argues that improved health outcomes are a direct function of the overall quality of life. Moving beyond a simple biomedical understanding of health and illness, it argues for considering the impact of various social locations on health. At a 2002 York University conference identified 14 SDH: “Aboriginal [Indigenous] status, disability, early life, education, employment and working conditions, food insecurity, health services, gender, housing, income and income distribution,

race, social exclusion, social safety net, unemployment and job security” (Mikkonen & Raphael, 2010, p. 9; Raphael, 2009). Furthermore, it argues for improvement in the real-life condition of these social locations, from poverty to discrimination to lack of access to services and beyond (Mikkonen & Raphael, 2010; Townsend, Whitehead, & Davidson, 1980/1992).

When health is understood through the SDH framework, social movements become a vital tool for creating social change that will improve health. I broadly define social movements as a group of people working to create social change, often through political action (Barbalet, 1988; Castells, 1997; Smith, 2009. See also Alinsky, 1989). Chapter 2 provides more information about social movements theory.

I define “community organizations” as various community service organizations, more broadly known as comprising the “third sector”. The concept of the “third sector” is sufficiently important to this research in that it warrants its own literature review below.

Finally, I define “funding policies” as the requirements and mandate imposed on providers of services and programs. In Chapter 5, I examined funding requirements to determine their impact on advocacy and community development efforts within the organizations under study. I looked at those funders who provide greater than 10% of community organizations’ budgets; for example, The *Public Health Agency of Canada* (federal), the *AIDS Bureau of Ontario* or *Ministry of Health and Long-term Care* (provincial), and relevant municipal bodies, such as public health departments.

Literature Reviews

This research rests on information from three related bodies of literature: 1) specific health risks faced by Ontario’s LGBTQ+ communities; 2) the SDH framework as it relates to

LGBTQ+ health; and 3) the changing nature of the broader third sector and community-based service delivery.

Health Risks of the LGBTQ+ Population/Ontario's LGBTQ+ Community

I first examine literature specific to the health risks of the LGBTQ+ community. The LGBTQ+ community has consistently demonstrated population-specific health needs, including a higher risk for HIV/AIDS and sexually transmitted infections (among MSM)., gay men and MSM continue to be at high risk (Public Health Agency of Canada, 2015). Gay men and MSM, especially racialized MSM, continue to display the highest HIV/AIDS rate among all other risk groups in the Western world (Centers for Disease Control and Prevention, 2015). Men who have sex with men are 19 times more likely than the general population to be HIV-positive (World Health Organization, 2013).

Advances in preventive drugs, such as pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP), have reduced the risk of HIV—at least for those who can afford the expense. Although these medications do not protect an individual from other sexually transmitted infections and are not foolproof, a recent trial found that a “daily dose of oral PrEP could reduce the risk of HIV transmission by up to 99% if adherence was high” (Young & McDaid, 2014, p. 196; Wilton, 2014). However, the drug is expensive—more than \$850 per month—and daily compliance is essential for it to be effective (McCann, 2014). Such medical advances have been characterized as ways to profit from the management of HIV prevention (Kerr & Mkandawire, 2012).

Moving beyond HIV/AIDS, research also indicated that lesbians often seek fewer medical consultations and pap tests than heterosexual women and due to heteronormative assumptions about sexual orientation, discrimination, and incompetent treatment (Abdessamad,

Yudin, Tarasoff, Radford, & Ross, 2013; Logie, James, Tharao, & Louffy, 2012; Tjepkema, 2008).

Bisexuals report the poorest mental health and greatest utilization of mental health services among the Queer population in both Canada and the United States due to high rates of childhood physical and sexual abuse; violent victimization and rape; biphobia (even within the LGBTQ+ community); post-traumatic stress disorder; and high substance abuse rates among bisexual women (Rainbow Health Ontario, 2011).

Trans people also pervasively face ongoing stigmatization and social exclusion, discrimination, violence, and poor health (Winter et al., 2016). While the number of Trans people globally continues to increase (Winter et al., 2016), they continue to face the greatest disparity, within the LGBTQ+ community demographic, in accessing healthcare. This has been attributed to a lack of clinical interest, training, and knowledge of Trans-specific health issues and treatments among physicians, an absence of ethical guidelines reassignment and transition surgeries, and a failure to recognize and accommodate Trans patients in a sex-segregated health system (Snelgrove, Jasudavisius, Rowe, Head, & Bauer, 2012).

Queer youth face another health inequity: they do not have access to appropriate sexual health education and resources (McKenzie, 2015). The lack of Queer sex education curricular content may also be a factor in young peoples' experiences of homophobia and transphobia in schools (McKenzie, 2015). An international study "indicated that many Queer young people feel unsafe in their schools and regularly experience verbal or physical abuse" (Schmitt, 2012, p. 374).

A number of studies have documented the LGBTQ+ community's greater vulnerability to clinical mental health problems (Kulick, Wernick, Woodford, & Renn, 2017; Pakula, Carpiano,

Ratner, & Shoveller, 2016; Veale, Watson, Peter, & Saewyc, 2017), substance use, (Public Health Agency of Canada, 2015) and homelessness (Abramovich, 2012, 2016). The increased awareness of these health risks calls into question governments' continuing medicalized emphasis on HIV and the lack of a broader LGBTQ+ health strategy that includes funding for Queer-specific health programs that take a more structural approach.

Sexual Orientation and Gender Identity and Expressions as a Social Determinant of Health

In Canada, the seminal document for the advancement of structural approaches to health is The Ottawa Charter for Health Promotion, (World Health Organization, 1986). As these approaches developed in health promotion, there has been a growing understanding of the “political, economic, social, cultural, environmental, behaviour and biological factors” in health and of the importance of advocacy to address these factors (World Health Organization, 1986, para 5). Although sexual orientation is sometimes included in the “list” of SDH, researchers question whether the current health literature and policy environment adequately address sexual orientation and gender identity and expression as an SDH. In some cases, the SDH framework actually subsumes sexual orientation under the concept of gender as an SDH, suggesting a lack of understanding at best and an underlying homophobia at worst (Mikkonen & Raphael, 2010; Raphael, 2009). Another problem with conflating gender and sexual orientation and gender identity and expression is that it neglects the debates and experiences of fluid sexualities and the differing health needs of the diverse groupings within the LGBTQ+ community.

Fortunately, Mulé and Smith (2014) point out, “[a] wave of recent research has highlighted the extent to which the social location of LGBTQ communities and the discrimination and stigmatization experienced by these populations may influence health outcomes” (p. 235). Mulé et al. (2009) examined models of health promotion in Canada,

including SDH, population health, and public health, and found “shortcomings and limitations that in effect exclude LGBT people and communities” (p. 9). In particular, they found that LGBTQ+ people were not adequately reflected in the language of Canadian health policy that refers to visible minorities, nor was there adequate recognition of the unique health issues facing LGBTQ+ people (Mulé & Smith, 2014). As noted above, these health issues include increased HIV and sexually transmitted infection risk (Hammond, Holmes, & Mercier, 2016; WHO, 2013), mental health and substance use vulnerability (Kulick, Wernick, Woodford, & Renn, 2017; Pakula, Carpiano, Ratner, & Shoveller, 2016; PHAC, 2015; Veale, Watson, Peter, & Saewyc, 2017), and vulnerability to physical and emotional abuse and violence (Logie, James, Tharao, & Loutfy, 2012; WHO, 2013), homelessness (Abramovich, 2012, 2016), and lack of health care access (Abdessamad et al., 2013; Snelgrove, Jasudavicius, Rowe, Head, & Bauer, 2012; Tjepkema, 2008; WHO, 2013). These risks are specifically related to the stigmatization, oppression, and social exclusion experienced by the Queer population—which need further examination as LGBTQ+-specific SDH.

Following up on Mulé et al.’s 2009 research on Canadian health policy and LGBTQ+, I examined whether the literature reflects an improved understanding of sexual orientation and gender identity and expression as an SDH since January 1, 2009. (Details on how the search was conducted can be found in Appendix A).

Similar to on Mulé et al.’s (2009) findings, I found that more than half of the articles reviewed tended to focus on how sexual orientation leads to behaviours, particularly sexual behaviours, that affect health outcomes; hence, there appears to a continued emphasis on HIV, sexually transmitted infections, and substance use (Halkitis, Wolitski, & Millett, 2013;

Hatzenbuehler, Bellatorre, Lee, Finch, Muennig, & Fiscella, 2014; Hidaka et al., 2014; Kuyper & Vanwesenbeeck, 2011; Oster et al, 2013).

This focus is still important. For example, among MSM, the last 20 or so years have seen a proliferation of bareback or unprotected sex, and even “bug chasing” (seeking out HIV-infected partners). However, a more nuanced understanding of these issues of the critique of our approach to understanding “risk behaviours”. “Risk assessment” itself is a major industry (Ewald, 1991; Holmes, Gastaldo, O’Byrne, Lombardo, 2008), framed by notions of individual responsibility to avoid “foolhardy, careless, irresponsible, and “deviant” behaviours (Lupton & Tulloch, 2003, p. 114). Such approaches to risk reduction or risk assessment, while effective for addressing some issues, can also be seen as heteronormative agents of behaviour-policing that functions to mask the political inequalities underpinning sexually risky behaviours (Lupton & Tulloch, 2003, Schuster et al., 2005). Others argue that the increase in bare-backing could be interpreted as a form of radical resistance to heteronormative socialization and the stigmatization of Queer sexuality (Haig, 2006; Hammond, Holmes, & Mercier, 2016; Holmes & Warner, 2005). McGregor (2001) has argues that the stigmatization of Queer sexuality can be traced back to the neoliberal valorization of individual freedom and the presumption that behaviour is an individual choice.

Furthermore, medical and behavioural harm-reduction approaches, such as a blanket “condoms-only” strategy, can be understood as a reflection of neoliberal ideology that offers individualized, “band-aid” solutions. This approach also highlights a default heteronormative framing of sexual behaviour, which does not align with gay sexual culture.

However, there is also evidence of an interest and understanding of the SDH for the LGBTQ+ community that goes beyond HIV and sexual behaviours. As early as 2003, Meyer

(2003) examined issues of “minority stress,” articulated through “stress processes” including both external homophobia (prejudices such as anticipating rejection and having to remain closeted) and internalized homophobia. (See also Hatzenbuehler, 2009). Krieger (2012) was among the first to suggest “eco-social” approaches to understanding the relationship between health and multiple types of discrimination and stigma, including among sexual minorities. Since then, however, there has been an increasing number of articles focused on the health implications of social stress, stigma, exclusion, and discrimination specifically as it relates to the experience of sexual minorities (Gahagan & Colpitts, 2017; Khan, Ilcisin, & Saxton, 2017; Steele et al., 2017; Zemman, Aranda, Sherriff, & Cocking, 2016). There is also increasing recognition of socioeconomic SDH such as housing instability and low income (Blosnich et al., 2017; Emlet, 2017; Ferlatte, Salway, Trussler, Oliffe, & Gilbert, 2018; Wade & Harper, 2017). These studies are a promising start to developing a broader, structural understanding of the specific determinants in LGBTQ+ health inequities and may improve the SDH framework’s approach to this population.

Third Sector

I draw from Laforest’s (2009, 2011) use of the term “third sector” (originally coined by Etzioni in 1973 in his article, “The third sector and domestic missions” to include non-governmental organizations, not-for-profit organizations, charities, volunteer-based organizations, and community-based organizations. I recognize the great variation in the development, political outlook, and nature of service provision and activity among third-sector organizations (Lewis, 1999). I acknowledge that the history of voluntary organizations also includes their role as a “vehicle for political participation and citizen engagement” (Laforest, 2011, p. 26). However, because my research focuses on the progression of a major component of

a radical social movement into more mainstream service organizations, I am ultimately interested in the impact neoliberalism has on the advocacy and health care policy development role of the selected third-sector organizations under study. In particular, I am interested in how neoliberalism has shaped the replacement of “services and functions previously performed by government and the market” (Laforest, 2011, p. 51) with those increasingly provided by the third sector. Laforest (2011) further argues, “...the term [third sector] emphasizes the sectors’ residual role in the face of public and market failure” (p. 51). I briefly review the literature addressing this concern, as well as other debates and issues raised in recent work about the changing nature of third-sector organizations. Finally, I review relevant extant studies of other similar third-sector organizations.

AIDS Service Organizations, which are also a part of the third sector, were started as grassroots organizations by Queer activists to address the escalating HIV/AIDS crisis in the early 1980s (Warner, 2002). The formation of these organizations began in Canada during Pierre Elliott Trudeau’s administration as part of the push for a “just society” (Government of Canada, 1969, p. 10). During the formative years, processes put in place to enable participatory democracy as well as commitments to greater equality, meant many third-sector organizations were well funded and supported between the 1960s to the 1980s (Rice & Prince, 2013). Third-sector organizations seemed ideally positioned to simultaneously define the social problems they tackled and to provide appropriate services with their government funding (Jessop, 2013; Miller, 1998; Shragge, 1997). This nature of this positioning changed, however, when core funding for advocacy and public education programs were terminated at the federal level, and the welfare state was eroded. This erosion started in the Mulroney Conservative government years (1984-1993) and continued during the Chretien, and then Martin, Liberal federal governments

extending through the recession from the early to the mid-1990s, (Burrowes & Laforest; 2017; Miller, 1998; Rice & Prince, 2013). These conditions gave rise to New Public Management principles (Baines & Cunningham, 2011; Cunningham, 2000; Hood, 1995), in the 1980s as a way of applying market principles to the actions, services and accountability requirements of the public sector (Baines & Cunningham, 2011; Farnham & Horton, 1993). The New Public Management policy approach emphasizes strategic management, efficiency, competition, decentralization, and quality improvement (Baines & Cunningham, 2011; Cunningham, 2000; Farnham & Horton, 1993), but results in governments and organizations outsourcing labour, as well as reducing pay and maintaining poor work conditions (Baines & Cunningham, 2011; McMullen & Brisbois, 2003).

As a result of these changes, the third sector faces bureaucratic criticism for being inefficient and lacking accountability (Rice & Prince, 2013). Significant cutbacks in Ontario led to a 21.6% cut in social assistance benefits in 1995 (Evan & Smith, 2015) and a clawback or “termination of funds to those non-profits not providing *core mandatory services* [emphasis added]” (Miller, 1998, p. 409) as defined by the government funders. This shift resulted in an overall decline in third-sector capacity, forcing them to “restructure” programs and services around government-defined priorities based on the principles of neoliberalism (Burrowes & Laforest, 2017; Evans & Smith, 2015; Miller, 1998).

Conclusion

My hope with this research is to provide insights for moving forward on LGBTQ+ health equity within an SDH framework. As the literature shows, HIV/AIDS, while important, tends to dominate the thinking about LGBTQ+ health, though recognition of the SDH for this community has started to emerge. This promising work that has been done to expand our understanding of

LGBTQ+ health points to a number of unconsidered and under-considered health challenges, many of which are urgent and serious, such as high suicide rates and homelessness. This research explores avenues to address these concerns, including understanding the impact of neoliberalism's ideology of scarcity (e.g., fear of taxation) on the community's ability to respond to structural sources and solutions for health equity. In particular, this research begins a discussion of how to create a structural analysis of LGBTQ+ health through Queer Liberation Theory.

As Armstrong and Armstrong (1983) pointed out long ago, "The purpose of any theory, and therefore its usefulness, rests on its ability to make transparent the opaque—to expose how the thing actually works" (p. 20). In the final analysis, this research demonstrates how Queer Liberation Theory can help to make the opaque reasons for a lack of interest and action on LGBTQ+ health inequities more transparent. By looking beyond the lip service paid to LGBTQ+ health inequities, this structural theory helps to disclose the underlying reasons behind the existence of health inequities in the first place. Because it is rooted in the history and current struggles of the movement, it questions heteronormative ideas about the nature of sexual orientation and gender identity and expression. Equally important, Queer Liberation Theory's structural analysis of neoliberalism exposes "how the thing actually works" so that community organizations can more effectively challenge the dominant ideology of "scarcity" (however daunting in the current political climate). To this end, I propose working for an LGBTQ+ health strategy as a vehicle to mobilize different ways of understanding and taking action on the serious health issues this community faces.

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Chapter Two: Methodology and Theory: The Journey that Never Ends

This manuscript-based dissertation is premised on three studies. This chapter provides the important aspects of the theoretical frameworks for each study. Social movement theory contextualizes all of the research. Queer Liberation Theory was foundational to this work. In addition, the social determinants of health (SDH) framework was used as an accessible way to discuss the structural nature of health inequities. This chapter describes the primary and auxiliary theoretical frameworks of each manuscript-based chapter.

Ontology, Epistemology, and Standpoint

My interpretative framework for this research draws on a critical, realist paradigm. The ontological assumptions within this critical framework are that “reality is based on power and identity struggles” (Creswell, 2013, p. 37). The epistemological beliefs within this framework include the notion that “reality is known through the study of social structures, freedom and oppression, power and control” (Creswell, 2013, p. 37). Realism recognizes that objects and structures exist independently from how they are conceived, that is, as an objective reality (Wilson, 1983). However, realism does not insist that this objective reality is “only knowable with certainty by means of direct, human sense experience” (Wilson, 1983, p. 166), such as quantified scientific enquiry. Nor does it preclude researchers understanding how their own standpoint and biases effect their enquiry.

As a structuralist social worker and community activist, who has had professional and volunteer experience with a number of the organizations studied, I do not consider my participants as the “other”. Instead, I am aware of my “insider status”. I am also aware of my privilege as a young, White, middle-class, educated, cis-gendered man, and my disadvantage as a person with an invisible, but severe, learning disability. These characteristics help me to

appreciate my privilege, and motivate me to effect positive social change based on my intersectional lived experience as a gay man with an invisible learning disability. While my experience of academic and social “otherness” and exclusion were amplified by homophobic and ableist learning environments in my youth, I persevered and flourished at university. My drive was strengthened when I excelled in academia despite being repeatedly told in high school that I could never succeed at, or even attend, university. I have sought to harness the privilege of having a post-secondary education towards a pursuit for social justice—a motivation that I have carried throughout my professional, community, and academic endeavours.

Overview of Theoretical Frameworks by Manuscript-based Chapter

Chapter 3, “Love, lust, and loss in the early age of AIDS: The discourse in the *Body Politic* from 1981 to 1987,” provides the historical context for my inquiry. I conducted a content analysis of the debates in *The Body Politic* during the 1980s to examine how the gay liberation movement negotiated the HIV/AIDS crisis. In addition, I conducted 10 interviews with people who had been active in the gay liberation movement and AIDS activism at the time. Various themes emerged from *The Body Politic* and the interviews allowed for reflection and analysis of those themes. Themes included debates about the transmission of the disease, government responses, or lack thereof, the risks to individuals regarding disclosure or diagnosis, and the risks to gay sexual culture. Through the debates and discussions in *The Body Politic*, I examined the interrelated networks of the social actors involved in the crisis: public health and the medical profession, and community organizations and leaders in the gay liberation movement (Tindall & Wellman, 2001). I also examined how *The Body Politic* allowed the movement to negotiate and mediate the lived experiences and ideology of the gay community, while also assessing the risk of HIV/AIDS and disseminating information about that risk.

My analysis attempted to illuminate how the work of *The Body Politic* on the issue of HIV/AIDS facilitated the development of bio-citizenship among gay men in Canada. I used the notion of bio-citizenship from Rose and Nova (2003) who define it as “all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species” (p. 2). I argued that *The Body Politic* represented what Rose and Nova (2003) consider “bio-citizenship from below,” because it helped the community to respond to “expert knowledge” and re-defined the issues, such as safer sex, into tangible and manageable strategies for the community. As such, I argued that *The Body Politic* represents evidence that the HIV/AIDS crisis was a defining moment for the movement.

Although I do not address social movement theory explicitly in Chapter 3, it guided my approach to the research and to my analysis, as explored through the notion of “bio-citizenship”. Theories of social movements, along with my own activism, contextualize my research. As such, I wish to focus on them here.

Social Movement Theory

Social movements represent a collective of people seeking empowerment to create social change through both social and political action for the shared needs and concerns of a community (Barbalet, 1988; Castells, 1997; Smith, 2009; see also Alinsky, 1989). Smith (2009) argues that, “social movements challenge the traditional boundary between state and society, public and private;” and blur the lines of what may have been considered private by arguing that “the personal is political” (p. 23). For the gay movement of the 1980s, the issues were very personal indeed, resting on the very fabric of sexual orientation, gender identity and expression,

and sexual characteristics. A key dilemma in the discussion about the emergence of HIV/AIDS is what it would do to the promiscuous gay sexual culture, as explored in Chapter 3.

Smith (2009) also argues, “social movements are often said to engage in strategies and tactics that are more radical than those used by interest groups” (p. 24). This includes working for social change through direct action and a more decentralized democratic organization. I argue that *The Body Politic* exemplifies Smith’s criterion of a social movement: it was run by a collective and was a tool for mobilization in the streets (McCaskell, 2016).

Another characteristic of social movements, as defined by Smith (2009), is that they may emphasize “the creation and reinforcement of identity and the promotion of certain values over the pursuit of material interest” (p. 23-24). However, the gay movement in the 1980s did not ignore the “material interests” associated with HIV/AIDS, such as the need for treatment, services, and the fight against discrimination in housing, employment, and other areas. The activist work of the movement of the 1980s, as I saw it in the pages of *The Body Politic*, fits better with Brady’s (2009) notion of a social movement. Brady makes an explicit connection between social movements and political economy. He argues that we should understand social movements as a group of citizens, sometimes from diverse backgrounds and communities, that come together to work for greater social equity, often through “a more generous welfare state” (Brady, 2009, p. 10). In this case, this manifested in the form of AIDS community organizations and access to medical services in the face of a health crisis.

In fact, many of the activists argued for revolutionary change that went beyond even “a more generous welfare state.” In the gay movement of the 1970s and 1980s, many “linked homophobia to capitalism and were influenced by socialist theories” (McCaskell, 2016, p. 7). McCaskell (2016) articulates the struggle in this way:

“clear distinction between struggles for democratic rights, aimed at equality within an existing social framework—and revolutionary struggles aimed at fundamentally changing that framework. Both were progressive, but they [reformers vs. revolutionaries] had different aims and involved different kinds of people” (p. 57).

Similarly, Vancouver’s Gay Liberation Front argued “that gay liberation had to consider itself part of a wider revolutionary movement, rather than concerning itself with problems of the gay community only” (Vancouver Gay Liberation, 1971, p. 2).

Clearly the gay movement of the 1980s reflects most of the aspects described in social movement theory. Furthermore, the movement was never totally cohesive. No doubt, some in the movement were more focused on identity issues than material issues. However, McCaskell’s (2016) characterization of some of the internal struggles point to what I perceive as important differences between the trajectory of the movement I saw in the pages of *The Body Politic*, and current Queer struggles. For me, this structural analysis provided the missing piece to the puzzle of why the early movement seemed so different from the movement I experience — a movement where debates about structural change are no longer prevalent. This structural focus within social movement theory informed how I approached the rest of my research for Chapters 4 and 5.

Social Determinants of Health Framework

Chapter 4, “LGBTQ+ and Ontario’s Health Care Policies and Programs,” was written with Nick Mulé and Maryam Khan, and uses a health equity lens, specifically an SDH perspective. We examined the websites of the Ministry of Health and Long-Term Care (MOHLTC) and each of Ontario’s 14 LHINs in 2009 and 2017 to offer insights into the health policy environments of these times. The analysis focused on whether and how LGBTQ+ health

issues were represented on Ontario government websites. These findings were complemented by interviews with bureaucrats.

I argue that the SDH perspective is not a theory per se, but proved to be a useful auxiliary framework, because it is well recognized and widely understood. As such, it provides a common language for discussing structural health inequities. Furthermore, there is a direct link between the SDH framework and social movements, because the SDH framework focuses on non-medical socio-economic factors, such as poverty, housing, and social inclusion, and their impact on health outcomes. If health is viewed medically, health solutions tend to be individual; when viewed socially, collective social action and public policy provide solutions. As Raphael (2009) argues, addressing the SDH requires “social movements that will force authorities to undertake positive policy change. These grassroots activities will involve community education and development, building of social movements, and shifting perceptions on the role of governments in assuring citizen security” (p. 160). The language of the SDH framework is widely understood. As such, it served as a tool for measuring whether study participants (bureaucrats in Chapter 4 and both bureaucrats and community organizations in Chapter 5) understand the structural underpinnings of health inequities.

Chapter 4 also identifies some of the shortcomings of an SDH perspective for understanding LGBTQ+ health issues and the policies developed to address them. As discussed in the literature review in Chapter 1 (and summarized in Chapters 4 and 5), LGBTQ+ health research and policy still tend to focus on HIV/AIDS and mental health. It also often emphasizes how being Queer influences behaviours rather than treating Queerness as an SDH. The latter approach focuses on how discrimination and other experiences become embodied as ill health, and gives greater recognition to issues of poverty and homelessness. Chapter 4 notes that

including experiences of sexual orientation, gender identity and expression as an SDH has only just begun, with a few promising studies exploring concepts such as “minority stress” (Hatzenbuehler, 2009; Meyer, 2003). Ultimately, this chapter concludes that an understanding of the SDH is not reflected in programs and services as they are described and emphasized on the MOHLTC and LHIN websites. Some local organizations, however, have shown interest and progress on LGBTQ+ health inequities.

Queer Liberation Theory

Chapter 5, “Perceptions and experiences with funding and policy-making for LGBTQ+ organizations,” explores how the work of local LGBTQ+ community organizations both shape and respond to current and evolving neoliberal funding policies. I wanted to study how much the politics of the movement, albeit as represented by a few organizations, had changed since the 1980s and how well current participants understand structural health inequities. The theory in this chapter draws primarily from Queer Liberation Theory, which also takes into account the history of the movement and the interactions among identity, social movements, and political economies, particularly the impact of neoliberalism.

As an emerging theory, Queer Liberation Theory shares Queer Theory’s insights regarding the fluidity of sexuality, but makes “space for all identities without judgement, including essentialist identities such as gay, trans, lesbian, and straight” (Mulé, personal communication, Feb. 1, 2018). Indeed, the use of the word “Queer” in addition to terms like “gay” or “LGBTQ+” is a deliberate move to expand notions and experience of gender and sexuality, that is, the essentiality and fluidity of both. In the terminology of Queer Liberation Theory, simply put, the use of the word Queer signals a progressive, critical, sex-positive, anti-assimilationist, liberationist perspective. The term LGBTQ+ is used to describe an assimilationist

perspective that strives for respectability and acceptance (Mulé, 2016). There are three aspects of Queer Liberation Theory, all at various stages of development: anti-assimilationism, notions of solidarity across social movements, and the political economy of Queerness.

Assimilationism vs. Anti-assimilation

Queer Liberation Theory's notion of inclusion emphasizes anti-assimilation. It does not celebrate diverse "role models" within existing structures, such as gay CEOs and racialized women in positions of power. Similarly, Queer Liberation Theory's analysis does not celebrate the corporatization of LGBTQ+ movements and sexual cultures. For example, the annual Gay Pride event, once a political demonstration, has been mainstreamed into a business and a family-friendly celebration of gayness (McCaskell, 2016; McKenzie, 2016). Core issues such as racism and poverty have been sidelined in order to focus on mainstream issues such as same-sex marriage and human rights campaigns.

The concept of anti-assimilationism is important because it divides the community between the "good gays," who mimic heteronormative relationships, from those more embedded in a distinct Queer culture. As Mulé (2016) points out, Queers who take advantage of marriage equality also become "morally" acceptable in a heteronormative society; whereas, those who reject the status quo of marriage are not. Penney (2014) makes the same argument:

[I]t's hardly counterintuitive to imagine that the apparently banal and conformist image of the suburban, upper middle-class homosexual couple with one point three children and two SUVs has the effect of radically calling into question the terms of the social bond [of marriage] as such. (p. 57)

Solidarity Across Social Movements

When I wrote Chapter 3 on *The Body Politic*, it was clear to me that the gay liberation movement was very much part of a broader left-wing social movement. As Lynch articulated in 1979, we need to avoid “the isolation of this one issue [gay liberation] from all the rest that concern us” (p. 26). I argue that a key feature of the “liberationist” perspective in Queer Liberation Theory draws us back to the coalitional and collaborative aspirations of solidarity across various social movements, such as women’s liberation/feminism, anti-racist, and anti-colonial movements, to name a few.

As an example of how thinking has changed, Pride Toronto in June 2016 was disrupted by an organization called Black Lives Matter Toronto. One of the issues they were protesting was the participation of uniformed police officers in the parade, despite the practice of “carding” and recent questionable police shootings of racialized men in Toronto and elsewhere. (“Carding” refers to the practice of police officers requesting identification and other information without probable cause.) Racialized men and other minorities are vastly over-represented in carded populations (Ontario Human Rights Commission, 2013). Some within the Queer community objected saying that “all lives matter,” including those of the police. For Black Lives Matter, and using Queer Liberation Theory, this latter position ignores the systematic inequality of racialized groups in the name of the supposed “progress” the Queer community has made (i.e., having police participate in the Pride Parade). Despite surface progress, there are broader, material, systemic issues within the LGBTQ+ communities, suffered more by some than by others. Indeed, Queer Liberation Theory’s concern with solidarity across movements arises from its understanding of political economy and what it is required to make transformative change.

Political Economy

Queer Liberation Theory gives equal weight to issues of structural inequality and sexual orientation, gender identity and expression and sexual characteristics. As such, Queer Liberation Theory raises questions about how social movements can both foster an anti-assimilationist identity and move beyond identity formation to challenge neoliberal ideology and social economic inequality. It is this structural, political economic aspect of Queer Liberation Theory, although relatively undeveloped, that had the most influence on this research.

One example of how this thinking could be applied is how Apple Corporation could be considered to engage in “pink-washing” human rights. While Apple champions a gay-friendly corporate culture and financially supports pride events in North America and Europe, it violates human rights and perpetuates hyper-exploitation of workers in off-shore factories that produce its products (Heisler, 2013). In 2012, the Human Rights Campaign Buyer’s Guide gave Apple a perfect score on “LGBT rights”, based on their policies and benefits (Human Rights Campaign, 2017). At the same time, there were documented complaints from Chinese factory workers about horrific working conditions, which in some cases led to workers’ suicides (Bilton, 2014; Cuthbertson, 2015). Queer Liberation Theory does not lose sight of social justice for workers regardless of issues of sexual orientation.

Consistent with a critical, structural framework, Queer Liberation Theory works towards an inclusive and equitable society that creates “discourses *and* real-life experiences that best meet the needs of gender and sexually diverse communities” (Mulé, 2012, para 1, emphasis added). As a small step towards the development of Queer Liberation Theory’s structural analysis, Chapter 5 examines the impact of neoliberalism on selected community organizations dealing with LGBTQ+ health issues. For this research, I do not apply a class analysis per se to

my research questions. Rather, I understand neoliberalism as the economic and political doctrine widely adopted in the classed societies of western capitalist nations starting in the late 1970s. Neoliberalism emphasizes free markets, state de-regulation, and the dismantling of the welfare state as the means to create prosperity for all (Chernonas & Hudson, 2007; Harvey, 2009; Navarro, 2002). This research examines the impact of neoliberal ideals of privatization, free markets, and a frugal welfare state on Queer activism as represented by the community organizations in the third sector studied here.

My definition of the third sector draws from Alcock's (2010) somewhat simplified model based on three socio-economic sectors: state, market, and civil society. According to this model, the state is associated with "formality, regulation, coercion, [and] redistribution. The market is concerned with "entrepreneurship, investment, accumulation, [and] competition" (Alcock, 2010, p. 8). Finally, the third sector, or civil society, values "association, mutuality, altruism, [and] democracy" (Alcock, 2010, p. 8). Bode (2006) and others (e.g., Enjolras, 2009) argue this relationship is undergoing transformation and blurring the lines among the sectors. For my purposes, however, I have placed community organizations in the civil society sector based on "the social provisioning" that they provide, and the fact that they are funded by the state but considered to be outside of government. For this research, I use the idea of social provisioning to include both "voluntary work directed at meeting needs in the community" (Hoskyns & Rai, 2007, p. 300) and paid work directed at meeting those needs, such as the work of the organizations in this study.

Feminist Political Economy (FPE) analyses address issues of gender relations and the welfare state (Bakker, 2007; Vosko, 2002). As such, an FPE analysis is helpful in providing insights for Queer Liberation Theory's structural analysis. Bakker (2007), for example, discusses

the “...neoliberal attack on social provisioning” (p. 545). She points out that the infusion of neoliberalism into the social provisioning provided by the third sector means that, “Privatisation ... is not only reflected in the privatisation of state assets... but also in privatisation of parts of the state from itself” (Bakker, 2007, p. 545). In other words, as the state’s responsibility for welfare provision has eroded over the last part of the twentieth century, the third sector increasingly played its role through a negotiated partnership with the state. As Lightman and Lightman (2017) describe it, “After 1984 and the election of a massive Conservative majority government under Brian Mulroney, fiscal policy in Canada (Keynesianism) was dramatically de-emphasized (p. 42). I am interested in the role neoliberalism has played in this development that Laforest (2011) argues has led to the replacement of “services and functions previously performed by government” with those increasingly provided by third-sector organizations (p. 51.) Milbourne (2009) raises the concern “that such [market-oriented] mechanisms may serve short-term state interests but devalue the very community-level work, which is increasingly being promoted to address challenging social problems” (p. 277).

Indeed, it is this supposed independence from government and rootedness in the community that is important in this research. It has been argued that the identity and function of the third sector have been compromised through its loss of core values as government funding exerts more and more control (Jessop, 2013; Rayside & Lindquist, 1992; Whelan, 1999). Thus, the third sector can be seen as losing its control to the state and thereby diminishing the identity it once held within the social movement. Others have noted that government funding tended to allow government to regulate the politics of the movement that produced the organizations in the first place (Cain, 2002; Jessop, 2013; Kinsman, 1987; Miller, 1998; Shragge, 1997). As Cain (2002) stated, “many of those once ‘in opposition’ now find themselves working within

established and assimilated ...organizations, where political critique is often muted and where organizational and service concerns can easily overshadow social change ideals” (p. 108). This contradictory dynamic of neoliberalism is an important consideration in this research. As Chapter 5 shows, neoliberalism manifests itself in unstable funding and precarious employment, extensive use of volunteer labour, increased pressures for accountability and bureaucratization, and strained relationships with funders. All of these conditions have implications for the independence and advocacy work of the organizations.

Conclusion

Consistent with the approach of critical social work, my original intent was to use an SDH framework for this research. As noted, the SDH framework has explicit connections to social movement theory, which provides the context for the overall analysis. However, in the course of conducting this research, the SDH framework required refinement to better understand the issues affecting LGBTQ+ health and Queerness as an SDH. Although the SDH framework proved to be a useful way to talk with participants about the structural aspects of LGBTQ+ health, its shortcomings regarding its understanding of Queerness led to the evolution of my framework. This evolution is evident both in the analysis of bio-citizenship (in the context of a social movement) in Chapter 3, and in the development of a Queer Liberation Theory analysis in Chapter 5. The nascent Queer Liberation Theory brings three elements together: identity, social movements, and political economy, particularly the political economy of neoliberalism and its impact on the Queer community.

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Chapter Three: Love, Lust, and Loss in the Early Age of AIDS: The Discourse in The Body

Politic from 1981 to 1987

Abstract

This paper explores the idea that the AIDS epidemic constituted a defining moment for the Canadian gay rights movement and illuminates the intricate power dynamics of the development of a community identity. Using grounded theory inductive and deductive content analysis, and interviews with activists from The Body Politic magazine, this paper considers notions of health “from above” and “from below” by examining relations between the community and government and their confrontation with medicalization and the medical profession. I also examine how the magazine reported and negotiated issues related to the community’s self-policing and “self-managed oppression” through efforts to promote “safer sex” and risk reduction.

Keywords: The Body Politic, HIV/AIDS, gay rights/liberation, safer sex, bio-citizenship

Acknowledgement: I dedicate this paper with gratitude to the activists of The Body Politic, and to the memory of those who have since died, for their devotion to social justice and gay liberation. Your work is woven into the fabric of our lives as we continue to build on your work. I would also like to acknowledge the Canadian Lesbian and Gay Archives for their invaluable assistance.

Considered the “house organ of the Canadian gay movement” (Bearchell, 2007, para 14), The Body Politic (TBP) is a rich source of the history of activism during the emergence of the AIDS epidemic. Writing from an activist perspective, Patton (1985) describes the urgency of the situation and its lasting impact on the gay and lesbian community: “AIDS organizing, [...], was significantly different from other projects [...] AIDS organizing means agreeing to build a community with people who could be dead in two months” (p. 16).

The Body Politic was published from 1971 until 1987. Over 80 regular correspondents in 21 Canadian cities, with international correspondents from Australia, New Zealand, the UK, the USA, and occasionally from Europe, wrote for the magazine. Contributors were activists in their own areas. No one owned TBP, and at first, no one was paid. Eventually, five paid staff coordinated the 80 plus volunteers (Bébout, 2003). Alan O’Connor recalls that, using consensus decision-making:

The collective were [about twelve] people who had been around and had volunteered, and were invited in an informal process to start coming to collective meetings.... And the collective was the ultimate decision-making body (personal communication, April 10, 2014).

This paper explores the AIDS epidemic of the early 1980s as a defining moment for the Canadian gay rights movement (Patton, 1985; Roberts, 1995; Smith, 2005; Silversides, 2003).

I examine how the emergence of AIDS in the gay community, particularly in Toronto, Ontario, illuminates the intricate and complex dynamics of the development of a community identity (Bunton & Petersen, 1997), and how TBP functioned as a grassroots or “from below” source of information by and for gay men in Canada. Using an inductive and deductive grounded theory framework (Berg & Lune, 2012), I reviewed TBP documents and uncovered themes

surrounding the publication's relevant and timely coverage of AIDS. I examine TBP as an artifact of social network analysis, which examines the interrelationship of various actors, organizations, groups, and individuals, cooperating to channel resources and knowledge and influence behaviour (Tindall & Wellman, 2001). I also examine how TBP gave coherence to the lived experiences and ideology of the gay community while also disseminating relevant knowledge surrounding the spread of AIDS. To this aim, my analysis focuses on: AIDS transmission as related to risk mitigation, government responses to the "AIDS epidemic", and individual HIV disclosure or diagnosis. These categories prevail throughout TBP. They were also selected as a result of discourse analysis found within the literature that shapes how we frame the history of AIDS among the gay population, and how we understand the work of our predecessors as it shaped the current state of HIV spread. Such analysis illuminates how TBP helps to facilitate "bio-citizenship" and "bio-power" among gay men in Canada.

Biological citizenship or "bio-citizenship" can be understood as the development of recognition and entitlements associated with the rights and responsibilities of citizenship, but largely based on some aspect of people's biology (Marsland, 2012; Petryna, 2002; Rose & Novas, 2003; Whyte, 2009). Rose and Novas's (2003) interpretation of bio-citizenship refers to "all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species" (p. 2). Rose and Novas (2003) observe that these processes may emanate "from below" and "from above". Bio-citizenship "from below" involves "pioneering a new informed ethics of the self—techniques for managing everyday life in relation to a condition, and in relation to expert knowledge" (Rose & Novas, 2003, p. 21). In contrast, bio-citizenship "from above" refers to "strategies for making up biological citizens" based on

unquestioned scientific dominance (Rose & Novas, 2003, p. 14). A close look at TBP illustrates the complexities between the layers of mitigating risk management during the 1980s. In reporting on the scientific findings related to AIDS and its transmission, the publication focused on both “witnessing disease” and “witnessing illness” from within the experience of those most affected by AIDS, and the risk of AIDS (Adam, 2011, p. 4). More than just reporting on facts, TBP gave individuals living with this illness a face, and gave gay communities an opportunity to redefine their identities amidst the hardships of this new “health crisis”. In “Living with Kaposi’s”, Lynch (1982) poignantly illustrates how AIDS signified a “self-betrayal of gargantuan proportions and historical significance” (p. 32) to the gay liberation movement by forcing its reliance upon the medical profession. The same article sensitively depicts the love story between two men, one of whom had passed away from AIDS: What I remember most ... Is the sparkle in his eyes. I can deal with most of it now, the hair going, the tits going, the face being drawn and tired. *But I do miss that sparkle ...* (Bruce, as cited in Lynch, 1982, p. 32).

Another article, “Dying to Live” by Hannon (1985), portrays an individual’s struggle to maintain his spirits, despite his looming death: I was really weak. I wasn’t hungry. Funny taste in my mouth. After a couple of weeks of that I couldn’t get out of bed in the morning I was so weak. My friend Lonny from downstairs had to come up and help me go to the bathroom. I had to have a pail beside the bed because I was throwing up... But I didn’t go to the doctor. I figured I’d get over it. That it was the flu (Black, as cited in Hannon, 1985, p. 28).

Although these depictions provided a face to AIDS, grassroots public health endeavours can have the paradoxical result of stoking racism, ageism, and even homophobia or AIDS-phobia, or can add to the stigmatization surrounding disclosure of an AIDS-positive diagnosis (Adam, 2011). Persistent AIDS visibility at the grassroots level led to a sense of fatigue

surrounding the illness which was having negative effects on the community by the mid-1980s. A 1984 article, “Complacency Threatens AIDS Groups”, pointed to the disinterest and lack of fear in AIDS, despite its rise among gay men. Ironically, the same efforts made by “from below” organizations like ACT to settle some of the chaos and panic surrounding the AIDS crisis also contributed to complacency surrounding treatment and research (Trow, 1984).

Voices Past and Present

To validate my textual analysis, I conducted ten in-depth (30- to 45-minute) interviews with prominent activists and contributors associated with TBP. Participants were recruited after reviewing TBP articles, snowball sampling through other TBP members, and from Rick Bébout’s online memoirs. Following ethics approval from the York University Graduate Program in Sociology, interviews were conducted from March to April 2014 by phone, in person, and by email, and were digitally recorded and transcribed. Participants consented in writing to being identified.

Interviewees included: Gerald Hannon, an editor and features writer; Ed Jackson, an editor; Tim McCaskell and Gillian Rodgeron, who covered international news; Ken Popert, who was in charge of news; David Rayside, who wrote editorials and spearheaded fundraising; Gary Kinsman, a writer who was involved with the legal defense efforts when TBP was raided; Alan O’Connor, a volunteer receptionist turned writer; Stan Persky, who wrote news and book reviews for the Vancouver “bureau”; and Richard Summerbell, who wrote editorials and features. Two other individuals were contacted but did not respond.

“In Search of Our Own Morality”

TBP was remarkable in how its treatment of on-going debates affected the queer community. Letters and articles from all sides of the debate were printed. The discourse centered

on whether AIDS was a “gay disease”, how to define and understand “risk”, and how best to act on “risk” in the context of gay culture.

As Ken Popert put it, “Promiscuity knits together the fabric of the gay community” (T. McCaskell, personal communication, March 14, 2014). The debates concerning promiscuity in gay sexual culture illuminate the interplay between health “from above” and “from below” in shaping gay men’s identity, culture, and citizenship. Public health and the medical community, as well as the government, were quick to blame gay sexual culture not only for the spread of AIDS, but also for its etiology (Patton, 1985; Sears, 1991). As Patton (1985) notes, some authorities considered AIDS an “elective disease created by homosexuals who might just as well die off” (p. 69). Popular “common-sense” medical columnist Dr. Gifford-Jones (aka Kenneth F. Walker) argued, “People with AIDS suffer from a self-inflicted disease and are un-deserving of society’s sympathy or [coveted] hospital care” (Lesk, 1986, p. 19).

As Altman pointed out (1986), “Neither blame nor guilt is a useful response to an epidemic”. He argued that the “... prevalence [of blame and guilt] in the discussions about AIDS underlines the volatility and the political implications of the disease” (p. 26). “From below” media sources like TBP began to deconstruct the complex questions surrounding blame and responsibility, and in doing so revealed that sexual behaviour was intimately tied to both identity and ideology: “For gay men, sex, that most powerful implement of attachment and arousal, is also an agent of communion”, which can fill the place of family and shape politics (Goldstein, 1983, p. 9-10).

The gay community responded to the “gay cancer” with skepticism coupled with a critique of the medical profession and the media’s “persistent capacity for major distortion in their coverage of gay-related issues” (TBP, 1981, p. 19). Referring to major North American

newspaper and media coverage, TBP lamented having to “...endure the publicity which sensationalizes another ‘gay disease’...” (Lewis & Coates, 1981, p. 43). In “Is there safe sex”, Bébout asserted that: “All advice is based on speculation. As should be obvious by now, anything said about the causes of AIDS can only be founded on theories, assumptions and arguments by analogy with other diseases—not on absolute knowledge of the nature of AIDS” (Bébout, 1983, p. 35). Previously, TBP collective member Michael Lynch had accused the medical profession of: “adding a potent new means of control. They seek to rip apart the very promiscuous fabric that knits the gay male community together and that, in its democratic anarchism, defies state regulation of our sexuality” (Lynch, 1982, p. 36). Lynch recognized the potential threat that biomedical fear mongering could have on the pride, sexual liberation, and solidarity of the 1970s gay rights movement. This fear was supported by the knowledge that the first victims of AIDS, as reported by the Centers for Disease Control, were gay men who did not previously know each other, nor had common contact or knowledge of partners with similar illnesses (Altman, 1986). Tim McCaskell describes the “early skepticism” and uncertainty in the community:

... [We] were less interested in the actual disease than ... the moral and social impact that it’s going to have on our community.... AIDS is both a political issue and a medical issue...and that we can’t let doctors tell us how to run AIDS. We can’t let public health tell us how to run AIDS. You know, we need to take charge (personal communication, March 14, 2014).

Ironically, by taking charge, the gay community and their grassroots efforts also reinforced AIDS as a “gay disease” (Altman, 1986, p. 39). As pointed out by Altman (1986), the gay community itself had the privilege of political will and resources to shed light on issues that

other more marginalized groups were unable to voice. The publication informed and shone an unflattering spotlight on a promiscuous gay lifestyle as the predominant cause for the spread of AIDS.

While the mass media drove a wedge between those within the gay community who lived “respectable” monogamous lifestyles, and those who engaged in “anonymous, public or promiscuous sex” (Kinsman, 1987, p. 192), the gay community itself started to experience divisiveness regarding what public health measures should be followed to ensure safety, without compromising identity. As more information on AIDS emerged, the debate broadened. Lynch (1982) recognized the need for good information regarding degrees of acceptable risk. Lewis (1982) described the situation: “Each of us has decided that some of these risks are necessary to make our lives fulfilling” (p. 39).

TBP reflected the unease and unknowns surrounding AIDS, with no clear representation of how life-altering the disease would be for the community. As one article noted: “Eighteen months after the symptoms of the disease surfaced, US medical researchers are still unable to explain its sudden occurrence in the gay male population” (Trow, 1982, p. 14). By reporting on both medical and governmental findings, while trying to uphold a “gay identity”, TBP, and the gay community itself, remained fundamentally linked to the patriarchal capitalist society that had ghettoized it (Kinsman, 1987).

In early 1983, many letters to the editor criticized the magazine for minimizing the severity of AIDS: “Featured articles on these subjects in TBP have yet to provide their readers with basic information about health risks” (Lawrence, 1983, p. 5), and, “By capturing our first glance you blatantly set the stage to discredit genuine attempts to understand this crisis” (Willoughby, 1983, p. 5). A few months later, Lewis (1983) confessed to underestimating the

severity of AIDS, stressing that multiple partners contributed to the risk: “If we choose to decrease the number of sexual partners we have, it should have the effect of reducing possible exposures...” (p. 11). Responding in TBP, Richard Summerbell (1983) feared that:

Lewis’s general comments on promiscuity struck me as overly optimistic.... Doctors have told us that we may make direct contact with the bloodstream by means of minute cuts and abrasions during anal sex.... All that’s required of us, in our “new sexual ethic”, is that we have sex in a way that favours us more than it favours our diseases (p. 6).

Some in the community erred on the side of caution in health education messaging. Like most medical workers at the time, Robert Trow, a paramedic at the Hassle-Free Clinic, was skeptical of a single-agent theory. Nevertheless, he acquiesced in the interests of community protection: “...on a poster, you have to go for the broadest and simplest advice that leads generally in the right direction” (Trow, as cited in Bébout, 1983, p. 35). When it came to the spread of AIDS, the “enemy” was universally and deeply embedded in ideologies of heteronormativity, and attempts to garner resources to contain AIDS were connected to an ongoing struggle to legitimize the category and worthiness of gay identity itself (Armstrong & Bernstein, 2008, p. 88). In the biomedical paradigm of “prevention as treatment” as the sole approach to gay male sexual interaction, the statistical significance of the illness itself was being abstracted from the context: the attributes of the individuals most affected by AIDS (Adam, 2011, p. 4). TBP fought hard against this abstraction by re-injecting individual perspectives and experiences into the conversation.

“Safe Sex or Else”

Throughout the magazine, “safer sex” was discussed and debated. All topics were covered in a non-authoritarian, non-judgmental way, speaking to the readership on their own

terms. New studies were introduced in layman's terms. TBP covered all sides of the debates surrounding: monogamy versus non-monogamy (or promiscuity) with personal examples (Bébout, 1986; Lynch, 1982), a hierarchy of risk activities (Bébout, 1983), dos and don'ts of lubricants (TBP, 1986), and a critical analysis of safe sex pornography (Demchuk, 1986).

Though oral sex was considered a low-risk sex activity by AIDS Vancouver, one 1986 article highlighted the need for more research, eventually deciding to classify oral sex as high-risk.

Other articles treated the subject humorously. Hutton covered safer sex preparations in daily life, by talking about using Crisco oil and calving gloves before an encounter (Hutton, 1986).

The first in-depth treatment of safer sex appeared in the December 1983 issue of TBP. Rick Bébout outlined what gay men could do to reduce their risk of exposure: limit the number of partners, choose partners carefully, avoid exchange of bodily fluids, know the risks of various sexual acts, and use a condom for some acts. By focusing on harm reduction versus a "condoms only" prevention strategy, TBP acknowledged that consistent condom use was not always possible (Adam, 2011). While this "from above" approach to safer sex may have been seen as a form of "intrusion on sexual behavior" and "one's gayness", TBP emphasized that "people had to consider making changes and altering behavior to lessen the probability of transmission of this illness, which we did not understand at all" (William, as cited in Bayer & Oppenheimer, 2000, p. 24).

Ed Jackson urged the community not to "fall prey to panic" and stop having sex, but to "...find a balance around this. And so it led to us ... supporting early on, messaging around finding ways to have safer sex" (personal communication, March 18, 2014). TBP linked safer sex to a new gay sexual ethic and identity. In December 1984, TBP reported on ACT's project

whereby seven gay men tried condoms “for size” and shared their experiences (Orr, 1984). The fear of AIDS as a sexually transmittable disease became too great to ignore:

I’m sure there was a doubt in the back of people’s minds, “Yes, okay, we should go to The Bath and educate, but what if it is poppers and cum?” But, you know, as time passed, it became clear that ... it was a virus of some kind or an infectious agent of some kind: blood-borne and semen-borne. That would make safer sex easier to endure (G. Hannon, personal communication, March 17, 2014).

Rick Bébout (1983) urged the community to take ownership of the crisis by discussing selecting sexual partners: “There’s also the danger here of subtle biases coming into play; our sense of what ‘looks healthy’ can be warped by considerations of class, age, race or sexual style that may have no bearing at all on how likely anyone is to have a disease” (p. 35). Here, Bébout references the social determinants of health (SDH), which encompass broader structural barriers to good health, as opposed to individual, biomedical explanations for health outcomes (Blaxter, 2010; McGibbon, 2012; Raphael, 2009). Although TBP framed AIDS and gay men’s health from within its own community and experiences, it also reproduced some of the same health disparities that it fought against. AIDS activists were generally educated, “white, middle-class men”, marginalized only by virtue of their sexual identity (Epstein, 1996, p. 65). Yet, we know that those traditionally disadvantaged and discriminated against based on socioeconomic status, race, gender, ethnicity, age, disability, and so on, *in addition* to sexual orientation, have systematically experienced “worse health or greater health risks than more advantaged social groups” (Braveman, 2006, p. 167). This makes a more inclusive “bottom-up” health promotion strategy imperative to implement in the present.

The gay community of the 1980s faced policing itself with risk-reduction techniques that undermined gay liberation and individualized the problem, and at the same time deflecting government responsibility for assigning resources to address it. As Lupton (1997) indicated, however, the social position of those practicing and promoting this self-policing complicates notions of risk, responsibility, and oppression. Hamburg elaborated: “As long as we view AIDS from the perspective of each of us trying to protect ourselves from others...we’ll run into trouble both politically and in sexual practices—period” (Bébout, 1983, p. 37).

The “top-down”, biomedical AIDS promotion approach to safer sex has failed time and time again because of this individualization. The resurgence of “barebacking”, or “bareback sex” (BBS), among a subpopulation of men who have sex with men (MSM) (Gastaldo et al., 2009; Holmes & Warner, 2005) confirms the need for a more reified, holistic approach to gay men’s health. BBS is a reactionary “form of resistance to the regulation and normalization of gay male sexuality” (Haig, 2006; Holmes & Warner, 2005, p. 862). It is, essentially, a bottom-up approach to a sociopolitical backslide into heteronormative “responsible sexuality” (Schmitt, 2012) dominating health discourse in the last 30 years, while completely disengaging from queer and trans lived experiences.

Government responses: “Chilling Indifference?”

Public health seemed more concerned with “protecting” the general population from the gay community as “vectors of the disease” (G. Kinsman, personal communication, March 16, 2014). The government’s slow response to HIV is mirrored in today’s implementation of the antiretroviral pre-exposure prophylaxis (PrEP), which has been found to drastically reduce the risk of HIV (Young & McDaid, 2014; CATIE, 2014). Though shown to be highly effective, controversy surrounds this form of safer sex: some insist that this is simply a “party drug” that

may not prove to be effective in the long run, and that it may lead to a culture of even more unprotected sex and the spread of other sexually transmitted infections (Hunter, 2014).

Controversy surrounding its efficacy and potential consequences for the gay community could contribute to its shaky status in Canada. Yet, similarly to the human papilloma virus vaccine for boys, the drug is not covered by insurance companies. Human papilloma virus is responsible for penile, throat, anal, and oral cancers, and is carried by 60% of men who have sex with men (a higher proportion than among women), and over 80% of HIV-positive men (Watson, 2015). Up to 90% of anal cancers among men result from some strain of human papilloma virus (CDC, 2014).

The delays in human papilloma virus vaccination and PrEP administration in Canada mirror the slow and reactionary response to AIDS that was covered by TBP 30 years ago. The Canadian government did not develop a national AIDS strategy until 1990 (Lenskyj, 2007). At the provincial level, Nova Scotia's health department spokesman, Dr. Wayne Sullivan, noted that in a small province like Nova Scotia there was no urgency to provide information to "high risk groups" as: "There's so much information already" (Jackson, 1983a, p. 15). Ontario Health Minister, Larry Grossman, did not find AIDS to be "'statistically significant' in the province" (Jackson, 1983b, p. 12).

Other levels of government were even less supportive. Ken Popert describes "the federal government's response to the AIDS epidemic as a bureau that was the equivalent of the American Centers for Disease Control. The funny thing is I could never get anybody to answer the phone... Years later, somebody told me... [anecdotally], 'Oh yeah, well, that phone's at an empty desk. Nobody was assigned to answer it'" (personal communication, March 18, 2014).

Richard Summerbell was at the Ontario Ministry of Health when the HIV laboratory was first established. He remembers that his co-workers were “totally committed to serving the community” and “wanted it to be done right” (personal communication). He noted that public servants were forbidden to speak to the public about AIDS: “We were absolutely clamped down” (R. Summerbell, personal communication, April 1, 2014).

The dearth of public communication regarding AIDS illustrates Sears’s (1991) point that “health from above” is characterized by the State demanding supremacy in protecting the community, often through inciting fear. “Health from below”, on the other hand, embodies the struggle by those affected to attain and maintain control over the power and resources they need to look after themselves (Sears, 1991). These struggles within various levels of government, as expressed in and by TBP, illustrate the power dynamics of bio-citizenship and an “incomplete” governance (Petersen, 1997) over the treatment of AIDS, with disparate and inadequate government responses across Canada from 1981 to 1985 (Sears, 1991).

The gay community, represented by TBP, recognized the urgency to steer the direction of its own health and the need for resources to do so. In January 1983, AIDS Vancouver became the first AIDS service organization in Canada, followed by the AIDS Committee of Toronto (ACT) (Jackson, 1983b). These two organizations were early attempts to address the unmet needs of the community with awareness, education, and support. Through action “from below”, the community challenged inadequate government support and action. In July 1983, ACT held a press conference to publicize its formation, and shortly thereafter the provincial government set aside a fund for AIDS research: “ACT members interpreted the province’s timing as a blatant attempt to undercut mounting criticisms of the government’s inaction” (Jackson, 1983a, p. 15).

TBP documented how "...AIDS patients [had been] caught in a web of government regulations" and bureaucracy (Joyce, 1986, p. 13) that sent a mixed and dangerous message to the gay community. For example, the gay community successfully argued that closing bathhouses would simply send activity underground. As Ed Jackson puts it, "The people who are best to do this kind of education and communication are the people in the community themselves" (personal communication, March 18, 2014).

From the community's perspective, Health and Welfare Canada's Health Protection Branch was slow to approve experimental AIDS treatment. Although they released drugs "on compassionate grounds", physician requests were denied unless they had access to a viral laboratory to monitor blood samples during treatment, services which were not uniformly available across the country: "Since the virus culture is destroyed in transit, BC patients can't use other Canadian labs" (Joyce, 1986, p. 13). This situation was resolved "from below" when Vancouver's gay and lesbian community fundraised to help people with AIDS travel to Ottawa for treatment.

Knowing or Not Knowing: Which is the Greater Risk?

In this context of ambivalence and confusion, the gay community took responsibility for tasks that should have fallen under the purview of universal health care. Within ACT, in conjunction with members of TBP, "two trends joined together" (E. Jackson, personal communication, March 18, 2014). ACT took on the political work of lobbying government and mobilizing education for prevention. ACT also supported those in the community who were living and dying with AIDS by initiating support groups and, eventually, hospice care.

AIDS testing and disclosure became an area of contention laying the groundwork for the collective voice of the gay community to regain some of its power. Initially, TBP discouraged

testing because of the uncertainty about the virus. TBP argued that the tests were unreliable, there was no cure or effective treatment, it was not clear whether some part of the population may be immune, nor was it clear what proportion of the exposed population would go on to develop AIDS (Jackson, 1985). Furthermore, it was not clear whether the presence of antibodies, as determined by the test, meant that the disease would be transmitted (Armstrong & Grenville, 1985, p. 37).

ACT and its allies in the medical community called for anonymous testing to prevent discrimination: “If we’re not careful, anti-body testing could become one of the most potent tools of gay oppression” (Aynsley, 1985, p. 17). TBP recognized that anonymous testing kept results under the control of the individual, preventing forces “from above” from using the results as a controlling mechanism.

Issues surrounding testing were handled with the same confusion and ambivalence characteristic of the Ontarian and Canadian governments’ treatment of AIDS. The Provincial Advisory Committee on AIDS, with representatives from the gay community, designed a test requisition form and two educational booklets for health care providers. The committee initially approved anonymous testing, but when the Ontario Ministry of Health reviewed the requisition form, it was altered to ensure that patients could be identified. Two weeks later, the Minister of Health “ordered that this situation be rectified immediately” to give patients the option of withholding names and using code numbers (Jackson, 1985, p. 15). TBP commented:

For observers ... it was a tangible demonstration of the challenge it presents to a minister intent on controlling public health officials imbued with traditional and entrenched notions of procedure (Jackson, 1985, p. 15).

Rayside recalls, “There were some health professionals who were in fact ... allies and [tried] not to let the AIDS issue be hijacked by a particular sexual morality.... There were certainly some struggles, I think, within the health profession around how to actually frame the AIDS epidemic” (personal communication, April 4, 2014). There was confusion within the provincial ministry around mandatory testing and reporting and apparent indifference from the federal government. Rayside attributes this to “some very conservative officials...who were absolutely not allied in the struggle to make AIDS more nuanced...” (personal communication, April 4, 2014). TBP shed light onto the continued struggle between the competing interests of a health “from above” versus a health “from below” response to the AIDS epidemic.

Love, Lust, Loss, and Questions Raised

The emergence of AIDS in the gay community, and the way in which TBP grappled with it, was a defining moment in gay history, identity, culture, and citizenship. As documented in TBP, the community’s response is evidence of a collective, politicized, and practical struggle “from below”—when public health “from above” was absent or oppressive. These struggles are sometimes portrayed as the clash of heroes and villains. David Rayside suggests, “...there is one version that points to health reformers as heroes” (personal communication, April 4, 2014), but the critical thinking at TBP allows us to understand the complexity of the situation and the power dynamics. Understanding these power dynamics allowed TBP to see beyond the discourse of AIDS as an objective, medical, scientific issue. Or, as Patton (1989) observed at the time, “‘Power’ is the grounding metaphor, along with notions of the ‘self’, by which people negotiate their resistance and their politics” (p. 31). She argued that the activism that arose from the early days of AIDS forced the community to understand and work with “the relationship between

unitary and network power” (Patton, 1989, p. 31). In this regard, TBP was remarkable in its ability to encourage a highly intellectual and thoughtful debate.

The frank coverage of the loss of life and struggle with AIDS found within TBP’s narratives encompassing risk management, government responses, and positive disclosure helps to illuminate the interplay between varying levels of governance on these issues. More importantly, it signified a shift in community identity and marked a certain loss of sexual freedoms. Perhaps this loss, as Persky underscores, can be attributed to:

...the difference between a gay movement founded on a liberation perspective and the recent period in which the gay movement, such as it is, with its “Pride” parades and weddings, seems more like an adjunct to the tourist bureau’s boosterism for ethnic festivals (personal communication, April 6, 2014).

The gay community’s loss, or self-managed oppression, echoes Petersen’s (1997) critique of “new” public health, which may be less controlling and coercive, but victim-blames. Kinsman (1996) argued that parts of the gay and lesbian community bought into the idea of “normalizing” themselves thereby creating a division between themselves and “irresponsible” queers. As Rayside recalls, even within TBP “...there was always contention.... It was never a unified voice” (personal communication, April 4, 2014).

The message that responsibility for health rests with the individual appears to remain today. Reflecting on the community and AIDS then and now, Tim McCaskell concurs that many of the functions of public health have been outsourced to “increasingly professionalized” AIDS service organizations, which “are now engaged in the policing of communities that formerly public health would do on its own...” (personal communication, March 17, 2014). Had “bio-

citizenship” been imposed “from above”, the loss for gay liberation would have been much more onerous. Stan Persky elaborates:

The name...perfectly encapsulated the ideas of the period.... [T]he gay movement was focused not simply on rights and/or equality (and certainly not on something like same-sex marriage), but on a notion of “liberation”. Gay liberation was part of a larger political (or “revolutionary”) proposal for alternative human relations and institutions—one that included feminism, racial equality, alternative education, therapy strategies, and counter-culture (personal communication, April 6, 2014; see also Hunt, 1992).

It is precisely this notion of “liberation” and its signification for the gay community that TBP strove to define for itself. The gay liberation movement continues to be defined and redefined through the gains and losses of the gay community. TBP can thus be understood as an important time capsule that helped make sense of critical shifts in a formative journey that continues to shape queer culture today.

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Chapter Four: LGBTQ+ and Ontario's Health Care Policies and Programs

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Abstract

The LGBTQ+ community experiences health inequities that are linked to the social determinants of health (SDH), though the full extent of these health inequities is not fully understood. This study is a comparative content analysis of the Ontario (Canada) Ministry of Health and Long-Term Care's (MOHLTC) website and the websites of each of the 14 Local Health Integration Networks (LHINs) in 2009 and 2017. It provides a snapshot and evaluation of the amount and type of online content concerning LGBTQ+-specific health needs and determines how well the programs and services aligned with the Ministry's stated priorities and population health/SDH philosophy. To further contextualize our findings, we also conducted seven semi-structured interviews with Ministry bureaucrats. We found disconnections between how (a) the MOHLTC presented its commitment to population health and SDH, and (b) how it articulated policy and delivered programs and services. Furthermore, the Ministry's broad policy approach appeared to show less emphasis on SDH in 2017 than it did in 2009. We also found very little LGBTQ+-specific content on the LHINs' website in both periods, with two notable exceptions in 2017. Our analysis revealed a persistent emphasis on HIV/AIDS risk containment in the LGBTQ+ community over the two periods. We argue that to promote healthy equity, the MOHLTC needs to acknowledge inequalities and intervene through political and social mechanisms that extend beyond HIV. We further argue that a provincial LGBTQ+ Health Strategy may provide one such mechanism.

Keywords: LGBTQ+ health, Ontario, population health, social determinants of health

Introduction and Background

Sexual orientation and gender identity and expression often appears on the “list” of international social determinants of health (SDH) (Blaxter, 2010; McGibbon 2012). Recent research has continued to highlight how the social location and the discrimination and stigmatization experienced by LGBTQ+ communities may influence health outcomes (Mulé & Smith, 2014). However, sexual orientation and gender and identity expression is not widely recognized as a specific SDH in Canadian public policy (Public Health Agency of Canada, 2018), and there remains inadequacies and restrictions that effectively disregard the health inequities faced by these individuals and populations (Mulé et al., 2009).

Health inequity refers to the systemic, population-based differences in health outcomes that are “structurally imposed and socially produced” (Graham, 2007, p. 36), and therefore “politically, socially, and economically unacceptable” (World Health Organization, 1978, para 3). A health equity lens challenges the medical model’s emphasis on illness-based health promotion by emphasizing the SDH including class, race, gender, culture and ethnicity, and education among others (Blaxter, 2010; McGibbon 2012; Raphael, 2009). When experienced in combination, these determinants, such as poverty and social exclusion, create “synergies of oppression” (McGibbon, 2012, p. 41). When health is viewed through this lens, one path to improved health is to “build social movements that will force authorities to undertake positive policy change” (Raphael, 2009, p. 160). This study evaluates the Ontario government’s online communications concerning their policies affecting LGBTQ+-specific health needs in order to provide evidence for Queer community mobilization around policy issues.

Specific Health Issues in the LGBTQ+ Community

The full extent of health inequities experienced by the LGBTQ+ community is likely not fully understood. Dharma and Bauer (2017) found flaws in definitions and measures of sexual identity in Canadian health surveys; for example, the restrictions of socially constructed identity categories may not capture the nuances of sexual behaviours and gender identity and expression. (See also Cahill & Makadon, 2017; Wolff, Wells, Ventura-DiPersia, Renson, & Grove, 2017).

Gay, bisexual, and transgender men, including Men who have Sex with Men (MSM)—but who do not necessarily identify as gay, bisexual, or Queer—continue to be at high risk for HIV/AIDS and sexually transmitted infections (Public Health Agency of Canada, 2015). However, the illness-based focus of most health promotion programs and services has overshadowed the LGBTQ+ community's diverse health inequities.

For example, the LGBTQ+ community faces barriers accessing services. Tjepkema (2008) found that LGBTQ+ Canadians from 18 to 59 years old had varying experiences with health care providers. Bisexual individuals in this study, when compared to heterosexuals, experienced marginalization and had many unmet health care needs. As well, lesbians have been found to consult doctors less frequently than heterosexual women and report having fewer pap tests (Tjepkema, 2008). Transgender people, in particular, face unique barriers to accessing appropriate health care regarding reproductive health and transition surgeries (Bauer, 2012; Bauer, Hammond, Travers, Kaay, Hohenadel, & Boyce, 2009). Access to appropriate sexual health education and resources for Queer youth are also ongoing health equity concerns (McKenzie, 2015). One international study indicated “that many Queer young people feel unsafe in their schools and regularly experience verbal or physical abuse” (Schmitt, 2012, p. 374).

The LGBTQ+ community also faces greater risks of mental health issues such as anxiety and depression, including higher risks of suicide and substance use (Kulick, Wernick, Woodford, & Renn, 2017; Pakula, Carpiano, Ratner, & Shoveller, 2016; Veale, Watson, Peter, & Saewyc, 2017), despite evidence that concerted community engagement with this population can have a significant positive impact on mental health outcomes (Crouch, Waters, McNair, & Powers, 2015; Kosciw, Palmer, & Kull, 2015; Toomey & Russell, 2011).

The Canadian Coalition Against LGBTQ+ Poverty recently demonstrated that this community is at risk for poverty (Canadian Coalition Against LGBTQ+ Poverty, 2018). Recent research documents mechanisms that create a noted wage gap between sexual minorities and heterosexuals (Waite & Denier, 2015). The LGBTQ+ community is also at higher risk of homelessness (Abramovich, 2012, 2016). One study estimates that more than one in five (over 20%) of youth accessing homeless shelters in Toronto identify as LGBTQ+ (City of Toronto, 2013).

Overall, however, our review of the literature found that research tends to address how SDH and sexual orientation and gender and identity expression affect behaviours, rather than conceptualizing it as an SDH. The emphasis on behaviours is reflected in the literature with the ongoing dominance of HIV/AIDS and mental health, especially substance use. Some recent research, however, has focused more explicitly on SDH. Literature on “minority stress” recognizes “stress processes” including direct experience of prejudice, anticipating rejection, having to remain closeted, and internalized homophobia (Meyers, 2003; Hatzenbuehler, 2009). Krieger (2012) offers the “ecosocial theory of disease distribution” (p. 936) that considers disease distribution in the context of social inequalities, including discrimination, which becomes embodied inequality and manifests as health inequalities. We argue that these aspects of health,

along with recently identified risks of poverty among this population, must be prioritized if we are to better understand sexual orientation and gender and identity expression as an SDH and to influence health policy and outcomes for the LGBTQ+ community. We sought to examine how well these concerns are reflected in the Ministry of Health and Long-Term Care's (MOHLTC) online communications.

Current Policy and Funding Environment in Ontario

In Canada's federated system of governance, health care is primarily a provincial and territorial responsibility. With a population of nearly 14 million, Ontario is the most populous and one of the richest provinces in Canada. Ontario's capital, Toronto, is home to one of the largest LGBTQ+ communities in Canada (Clarke & Coughlin, 2012). According to the 2015 Canadian Community Health Survey, 1.7% of people between 18 and 59 years old identified themselves as gay or lesbian and 1.3% of people in that age range identified as bisexual (Statistics Canada, 2016). The Canadian Community Health Survey does not include Trans populations and likely underestimates all Queer communities, as often occurs with stigmatized groups of people.

Ontario's Ministry of Health and Long-Term Care decentralized health care oversight by setting up 14 Local Health Integration Networks (LHINs) across the province in 2005 (Bill 36, Local Health Integration Act, 2006). One LHIN website explains the stated principle behind this decentralization: "local people are best able to determine their health service needs and priorities" (Central West LHIN, 2014, para. 1). The LHINs oversee hospitals, community health centres, long-term care facilities, mental health and addiction programs, and other community supports. More recently, the LHINs have taken responsibility for co-ordinating home care services (CBC, 2017).

Gaining authority in 2007, each LHIN determines its own process, format, and frequency of community engagement to develop an annual Local Integrated Health Service Plan. Although LHINs make funding decisions based on local needs and priorities, programs and services must still meet provincial strategic directions (Central LHIN, 2017). All LHINs are listed on a centralized hub (www.lhins.on.ca) that provides links to each of the 14 LHIN websites. As such, these web resources are the LHINs' public face and a key point of contact to access information.

Methods

This study is primarily a content analysis of the MOHLTC's website and the websites of each of the 14 LHINs at two different points in time, from September to November, 2009 and again from July to November, 2017. These dates were chosen to align with another study (Mulé et al., 2009) and because Rainbow Health Ontario was formed in 2009 as a province-wide MOHLTC-funded program promoting LGBTQ+ access to services and health promotion.

The purpose of this content analysis is to understand the Ministry's publicly-reported and self-defined approach to administering its mandate and whether its self-described policy approaches embraced population health and/or SDH frameworks. A population health approach is a well-recognized social model of health compatible or even synonymous with an SDH perspective because of its emphasis on multiple strategies to address multiple SDH and on prevention through "upstream interventions" (Government of Canada, 2012). Further, this content analysis determines whether these policy approaches were reflected in the LHINs' funding of services and programs for LGBTQ+. Finally, we examined whether the content changed over the two time periods.

We used the following search terms: bisexual, gay, gender identity and expression, homophobia, lesbian, LGBT, transgender, transsexual, Queer, sexuality, and sexual orientation.

We also paid particular attention to HIV/AIDS content, given its past and continued impact on LGBTQ+ communities. With regard to HIV/AIDS, we examined which populations were named and whether intersections of social locations were recognized.

To further contextualize our findings, we identified 17 municipal, regional, provincial, and federal funders and/or policy makers, including LHIN staff in the Greater Toronto and Hamilton Area (in 2017 only). We began our snowball sampling process (Babbie & Rubin, 2008) by identifying MOHLTC staff based on their positions in the online organizational chart. These individuals recommended MOHLTC staff who were in a position to speak knowledgeably about the issues under study. The organizations under study also recommended bureaucrats that they deal with, which led to the inclusion of municipal and provincial bureaucrats in the sample. We requested in-depth interviews, and nearly half (n=7) agreed to be interviewed. No one from the LHINs agreed to be interviewed, thus all levels of bureaucracy except the regional level were represented in the sample. Only those interviews with MOHLTC staff are reported in this study.

During interviews, we asked about informants' roles in policy formation, collaboration with the community, perceived political restrictions on their work, and perceived policy impacts. Findings from interviews, which had been coded according to a pre-determined coding scheme based on the interview questions, were concurrently analyzed with the content analysis findings. Informant quotes are identified under the general term "bureaucrats" because some participants were policy makers, some were funders, and some filled both roles.

Ministry of Health and Long-Term Care Website

For both time periods (2009 and 2017), we searched for mention of the LGBTQ+ population or its component populations. Also, for both time periods, we assessed how well the Ministry's stated commitment to a population health philosophy aligned with the actual

programs and services that were emphasized in the content of the website. To do this, we categorized programs based on their main focus and found that they could be organized under four themes: “benefits” (e.g., covered health services or programs), “health issues” (e.g., illnesses or diseases), “social locations” (e.g., age, race, gender, SDH, etc.) and “systemic operations” (e.g., health service provision functionalities such as accessing to services). We also assessed how much emphasis a program or service received on the website by identifying whether their mention occurred in more than one of the categories.

Local Health Integration Network Websites

In addition, we conducted a content analysis of the 14 websites for the LHINs. We examined the amount and nature of information presented, the programs available, LHIN-led consultation activities, and any publications created that were targeted to LGBTQ+ populations. For the LHIN websites, these search terms yielded various sources of data: technical reports produced by the LHINs, meeting minutes, PowerPoint presentations, website content, and news releases. LHINs were categorized for the amount and type of LGBTQ+ content for both time periods as follows: 1) minimal or absent LGBTQ+ content, 2) limited LGBTQ+ content, and 3) LGBTQ+-specific content. The “minimal or absent” category applied when LHINs’ website content made no mention of LGBTQ+ or simply listed LGBTQ+ among “priorities” in its materials but did not expand on goals or targets. Website content was categorized as “limited” when there was information about LGBTQ+ unique health needs, but with little evidence of community consultation and/or emphasis on LGBTQ+-specific services. Website content was categorized as “LGBTQ+-specific” when initiatives with a LGBTQ+ focus were highlighted or a clear articulation of LGBTQ+ diverse health needs was provided, or past and planned collaboration with the community (e.g., advisory committees, community surveys) was indicated.

Findings

Ministry of Health and Long-Term Care Websites: 2009 and 2017

Our analysis showed that there are disconnections between the MOHLTC's stated commitment to population health and SDH (MOHLTC, 2017a) and how it implemented policy and delivered programs and services, particularly regarding LGBTQ+. This was evidenced in the categorization of its programs and services that placed a heavy emphasis on service accessibility and delivery over social locations and the particular populations therein. Such disconnections were further corroborated by the bureaucrats we interviewed; however, other bureaucrats expressed hope that a better connection would emerge over time. The Ministry's broad policy approach showed less emphasis on SDH in 2017 than in 2009. Our analysis also showed a persistent emphasis on HIV/AIDS risk containment in the LGBTQ+ community over the two periods.

In both time periods, the MOHLTC website highlighted two main areas: governance issues and broad policy approaches. In 2009, the MOHLTC indicated its transition from a centralized to a regionalized approach, but with a process to filter the LHINS' decisions back up to the MOHLTC to ensure overall adherence to its priorities (MOHLTC, 2009a). Eight years later, the MOHLTC elaborated on this "new" mission and mandate is "stewardship": providing "the overall direction and leadership for the system, focusing on planning" and "guiding resources to bring value to the health system," (MOHLTC para. 2, 2017a). This reorganization involved little relinquishment of power: the branches of the MOHLTC were reorganized and decision-making processes were transformed and increasingly distanced from actual health care delivery.

Categorization of Services and Programs

Reviewing the categorization of services and programs the MOHLTC offered in 2009 and 2017 paints a picture of the extent to which population health and SDH were taken up for the diverse populations in Ontario, and LGBTQ+ in particular. When the 28 general MOHLTC programs were categorized on the 2009 website, it became clear that “health issues” (diseases and conditions) and “systemic operations” dominated, with eight and seven program listings respectively, indicating an illness-based focus and preoccupation with operationalizing the programs of the largest and costliest ministry in the province. Additionally, four programs in each of these categories were considered combined because of their intersections with each other. Examples of combined programs include immunization offered under “benefits,” “health issues” and “systemic operations;” organ and tissue donation under “health issues” and “systemic operations;” and Telehealth Ontario under “benefits” and “systemic operations.” Only children and seniors could be considered social locations as singular targeted programming in 2009 (MOHLTC, 2009b).

In 2017, the MOHLTC increased its listings of programs and services to 36, of which 19 were categorized as “systematic operations” dealing with provincial health programming administration and providing information and means of accessing services. There was a noted increase in the number of listings in social locations category, specifically within combined programs, such as people with disabilities, children, pregnant women, and seniors (MOHLTC, 2017c); yet, LGBTQ+ were not identified separately. Similarly, well over 90% of the MOHLTC’s online publications were focused on specific health issues or benefits rather than issues for specific populations. The only categories in the latter were children, youth, and

heterosexual women, identified both in 2009 (MOHLTC 2009b) and 2017 (MOHLTC 2017d), yet none dealt with lesbian, bisexual, and Trans women's issues.

Despite what we found to be an increase in content related to social location, it remains the most minimal of all the categories and pays little attention to LGBTQ+ communities. In short, the Ministry focused heavily on benefits, health issues and diseases, and systemic operations categories, with far less attention the social locations of Ontarians.

Children, women, and seniors were the only social locations identified on the 2017 website, with little attention paid to their SDH other than their health needs and access issues, and only minimal attention to how their social location has a direct impact on their health. Programming described on the website did not emphasize population health in 2009 and 2017. Rather, the majority of the public content focused on accessibility to the provincial health insurance system, medical care, emergency care, home care, and prescription drugs. This was particularly the case in 2017 (MOHLTC, 2017a).

HIV/AIDS-focused Content

In 2009, the MOHLTC used what is considered sensitive wording in the LGBTQ+ community: gay and bisexual men are explicitly and primarily named ahead of the epidemiological term "Men who have Sex with Men (MSM)" (MOHTLC, 2009c, d, e). Concerns have been raised both in the community and the literature regarding the obscuring effect the term "MSM" can have over men who self-identify as gay or bisexual (Mulé, 2005; Young & Meyer, 2005). The site identified other specific social locations and HIV/AIDS, such as people from Africa and the Caribbean, people who use injection drugs, Indigenous people, and women (MOHLTC 2009 e, d). These populations were discussed only in the context of HIV/AIDS.

These populations also are included in 2017, yet interestingly, the term “MSM” is no longer used, despite the fact that MSM continue to be at risk for HIV and are a target for HIV programming in the community. Despite this noticeable change in language, one bureaucrat said, “Certainly within the anonymous HIV testing program, there’s a very clear mandate to include MSM... [O]verall, the public health standards have us look at populations that may be at risk.” (Bureaucrat 6). Furthermore, these populations are discussed solely within the context of an illness-based program, specifically HIV/AIDS and the discussion lacks any mention of the intersectionality of the various social locations or SDH (MOHLTC, 2017b). The only area where the website hints at understanding intersectionality is where it discusses the interaction of women with one or more social location such as African, Caribbean, or Indigenous women, and/or women who use injection drugs (MOHLTC 2017b). Despite this absence of a population-health or intersectional approach in the website content, one interviewee noted, “Interestingly, the MOHLTC does use a population health approach for HIV/AIDS and funds these programs through organizations not funded by the LHINs” (Bureaucrat 5). Another bureaucrat acknowledged a move in the community towards a broader health mandate rather than a singular illness-based approach, which would inevitably capture an SDH perspective: “Well, that’s definitely the shift we’re seeing. A lot of ASOs [AIDS Service Organizations] are moving away from being sort of just addressing HIV, and they’re becoming more actually addressing gay issues in general...or gay sexual health issues.” However, the informant also noted, “Well, it would be a big shift.” (Bureaucrat 7).

Local Health Integration Network Websites: Main Findings

Our content analysis of the 14 LHINs websites led to three main findings. First, we found a remarkable lack of LGBTQ+ content in general and little change in the amount and type of

content between the two periods. Second, those LHINs that made an effort to consult the LGBTQ+ community also produced the only LGBTQ+-specific content that we found. Third, among those websites with only a limited amount of content, a number of interesting issues directly related to the SDH were raised, somewhat incidentally and usually in documents reflecting an interaction between the LHIN and the LGBTQ community or providers working in the community. For a comparative breakdown of the amount of LGBTQ content on LHIN websites in 2009 and 2017, see Table 1.

Table 1: Level of LGBTQ+ Content on LHIN Websites, 2009 and 2017

Level of Content	Number of LHINs (n=14)	
	2009	2017
Minimal/Absent	12	8
Limited	2	4
Specific	0	2
Total	14	14

Lack of Content

As shown in Table 1, in 2009, no LHINs included LGBTQ+-specific content on their websites. Only two had what we categorized as limited content: Waterloo-Wellington and Toronto Central. Among those LHINs with minimal or absent content, five showed some awareness of specific LGBTQ+ health issues, discussing the community in terms of population health. For example, LHINs identified LGBTQ+ as an underserved and underrepresented community (Mississauga Halton LHIN, 2009; Central LHIN, 2009), or as a higher-risk population (Central East LHIN, 2009) with specific health and service needs (South East LHIN, 2009) requiring culturally sensitive attention (Mississauga Halton LHIN, 2009). The Central West LHIN made its first mention of LGBTQ+ populations in 2010.

By 2017, there was a moderate increase in the recognition of LGBTQ+ community health needs. More than half of the LHINs (8) had minimal LGBTQ+ content, four had limited content and two had LGBTQ+-specific content, discussed in more detail below.

The Central LHIN provides an example of minimal content in a 2015 call for proposals for funding new services, because it merely “listed” LGBTQ+ as one of many equity criteria (Central LHIN, 2015). Similarly, in 2014 and 2017 the Central East LHIN identified the LGBTQ+ demographic among their priority populations in their addictions and mental health strategy (Central East LHIN, 2014, 2016) and referred to LGBTQ+ identity in reports (Central East LHIN, 2017). The South West LHIN (2011), Champlain LHIN (2016), and the Erie St. Clair LHIN (2013) identified unique LGBTQ+ mental health and addiction vulnerability, but only in the context of the needs of various minority groups requiring targeted education and programming (Champlain LHIN, 2016; Erie St. Clair LHIN, 2013; South West LHIN, 2011). A commissioned strategic plan for the Erie St. Clair LHIN in 2012 on adult mental health singled

out the LGBTQ+ population; however, this was not posted on the website. It was posted elsewhere.

Other LHINs stated a commitment to diversity, while simultaneously showing a serious lack of understanding of LGBTQ+ issues. For example, the Erie St. Clair LHIN did not develop LGBTQ+ content for their website, despite citing “diversity” as a key principle to “guide the development of health care” (Erie St. Clair LHIN, Para. 1, 2014). This LHIN defined “Gender,” as a male/female binary, rather than as a fluid construct. Similarly, a report on the South East LHIN’s site addressing SDH makes no mention of sexuality and/or sexual orientation; rather, this document actually conflates gender and sexual orientation (South East LHIN, 2014a, b). The South West LHIN noted that the small number of LGBTQ+ in the region made data collection and analysis difficult (Gilliland, Clark, Sibbald, & Tillmann, 2016).

Impact of Community Consultation

Despite the lack of content on the Waterloo-Wellington LHIN website in 2009, their Integrated Health Service Plan noted that they had completed a survey of the LGBTQ+ community in 2009. The 2017 site provided a detailed report of this consultation with comprehensive recommendations for raising awareness, providing services, improving service integration, and increasing provider training. The report also called for the LHINs to provide regional leadership for becoming an LGBTQ+ safe space and encouraged all health service providers to do the same (Waterloo-Wellington LHIN, 2014, para 8). This LHIN specifically argued that “[s]exual orientation and sexual identity should be considered social determinants of health as they fundamentally impact health status (Waterloo-Wellington LHIN, 2014, para 7).

The Toronto Central LHIN had also developed a 2009 community consultation on mental health and addictions (Toronto Central LHIN, 2009; Zanin, 2009). They developed a voluntary

“citizens’ panel” through which the LHIN consults with its diverse residents on matters related to shaping the health care system. The citizens’ panel had representation from many groups including Métis and trans-identified persons (Toronto Central LHIN, 2014, para. 6). By 2017, this LHIN had also undertaken an *Aboriginal Health Needs Assessment*, including survey questions for two-spirited individuals² (Schein, Jackson, James, Dopler, Pyne, & Bauer, 2013). The 2017 content of Toronto Central LHIN site reflected these consultations—with as many as 300 people—in that it recognized the internal diversity of the LGBTQ+ community, including the recognition of health risks associated with different age groups (Toronto Central LHIN, 2016).

Limited Amount of Content

In 2017, there were four LHINs that posted a limited amount of content. While the Central West LHIN (2009) lacked LGBTQ+-specific content, their report, *Diversity and Equity Core Action Group Meeting*, indicated a need for more statistics on marginalized communities such as “LGBT” (Central West LHIN, 2010). In their 2011 and 2012 environmental scans, LGBTQ+ were listed as a priority population (Central West LHIN, 2011, 2012). In 2016, this LHIN’s diversity and health equity core action group enumerated ongoing plans to engage the LGBTQ+ community in its meeting notes, including collaboration with a non-profit organization to increase the LHIN’s knowledge of LGBTQ+ (Central West LHIN, 2011, 2012, 2016, 2017). Interestingly, meeting minutes also highlighted the “uncomfortability of asking the LGBT questions” and recommended better training for health professionals (Central West LHIN 2016, p. 3).

² Indigenous (First Nations, Inuit, and Métis) persons who identify as trans might also use the term two-spirit. This is an umbrella term specifically for First Nations/Indigenous persons who are socially located between female and male gender roles. For further information, see, Anguksuar, 1997 and Balsam et al., 2004.

The Mississauga Halton LHIN, as of 2010, had taken some measures to incorporate LGBTQ+ content, including a reference to positive space training (Mississauga Halton LHIN, 2014a). Their website identified the need for “advancing health equity” (Mississauga Halton LHIN, 2014a, p. 6) through their Integrated Health Service Plan 2016-2019, with specific reference to sexual orientation (Mississauga Halton LHIN, 2014b).

“Incidental” Content

In addition to the coded content, we came across some interesting information incidentally. The North East LIHN mentioned LGBTQ+ populations only in 2016 during a board of directors’ teleconference meeting. Interestingly, the community needs identified were SDH: the need for LGBTQ+-inclusive living environments, staff sensitivity training on LGBTQ+ issues, inclusive language, and greater community engagement. Members of the teleconference also recognized the often-overlooked issue of inclusive living arrangements specifically for bisexual and transgender residents (North East LIHN, 2016).

Other LHINs made singular or few mentions, but in doing so, they highlighted important health issues in the community. The only content about LGBTQ+ populations posted by the North West LHIN (2017) was a presentation from service providers describing the lack of services and supports, which was corroborated in a Health Quality Ontario’s 2016³ review of services and programs in this LHIN (Health Quality Ontario, 2016). The North Simcoe Muskoka LHIN makes a singular but interesting mention of LGBTQ+ in a description of the inclusion of LGBTQ+ individuals on a 2015 patient-caregiver-family advisory panel (North Simcoe Muskoka LHIN, 2016).

³ Health Quality Ontario (HQO) is an agency that exists to educate the Ontario government and the many health care providers on providing the best care possible, based on evidence (research). The aim is also to inform the public about the quality of care and monitor its delivery.

Disconnections and Contradictions

As noted, our analysis showed disconnections between the MOHLTC's stated commitment to a population health/SDH approach and the content posted on its website. Bureaucrats we interviewed acknowledged the absence of LGBTQ+ health issue in key MOHLTC documents and frameworks, including their key framework document, "Patients first: Action plan for health care" (MOHLTC, 2018). One bureaucrat noted, "I don't think there's any references to LGBTQ in 'Patients First'" (Bureaucrat 3) despite an expressed interest in including LGBTQ+ in policy. Another bureaucrat remarked:

[T]here has been a tradition of or a history of a lack of services in specific communities, whether that's Indigenous communities or services to the LGBT community. You know, we need to make sure that the metrics we build into the policies we're developing reflect the satisfaction levels and the outcomes we wish to see in those communities. (Bureaucrat 1).

Another bureaucrat concurred with our reading of the website material that most strategies are based on health issues, not populations: "We don't have a lot of population-specific health strategies. There are usually issues-based, so we have an opioid strategy, we have a mental health strategy, and we consider all populations within those issue-specific needs" (Bureaucrat 4).

In contrast to our findings that showed little attention to LGBTQ+ issues, a MOHLTC bureaucrat stated: "[W]hether it's through local clinics or service delivery or working with advocacy groups, some do research, others do data collection, but you know, most of the LHINs do...a lot work [with] local LGTBQ community populations" (Bureaucrat 4). Verifying the extent of the LHINs' work on the ground was beyond the scope of this paper, but the public

websites reported little work directly focused on LGBTQ+ populations. Indeed, only the two LHINs that undertook consultations created what we considered to be quality information on their public sites.

One bureaucrat raised a concern regarding communities in which LGBTQ+ members have not organized: “[H]ow do you make communities where communities don’t exist?” (Bureaucrat 2).

LGBTQ+ Health Strategy?

When MOHLTC staff were asked specifically about the possibility of an LGBTQ+ strategy, one bureaucrat acknowledged: “The current structure probably is not adequate and probably there needs to be a program that’s probably specific to LGBTQ+ populations. So that’s in the works.” (Bureaucrat 7). However, we found no evidence that an LGBTQ+-specific program was in development. Indeed, another interviewee corroborated our perception of the MOHLTC’s illness-based focus: “One of the things that we have done in the development of the dementia strategy is to make sure that we are looking at ways to reduce inequity and provide services to the LGBT community in a culturally competent way.” This person highlighted that their consultations showed that the LGBTQ+ community faces challenges in getting senior services and specifically dementia services, because of persisting homophobia, with the result that many older adults are forced into the closet (Bureaucrat 1).

Discussion

Our study’s aim was to evaluate the amount and type of LGBTQ+ health content on the MOHLTC’s and LHINs’ websites in 2009 compared with 2017. Our research also reveals that the Ministry’s public information about LGBTQ+ health has been consistently inadequate between 2009 and 2017. Despite the claim of a population health approach and SDH perspective,

the MOHLTC public website content is organized according to an illness-framework. Most information about programming focuses on access to health care with very little attention to the SDH; only some specified groups such as people with disabilities, children, pregnant women, and seniors, were accorded pages on the sites. We also found little change between 2009 and 2017 as to how the MOHLTC presented itself.

This lack of a population health approach hinders *equitable* health care delivery and our ability to fully address the SDH (Blaxter, 2010; McGibbon, 2012; Raphael, 2009). We argue that a population health approach with an SDH perspective would better recognize the specific health needs of at-risk, minoritized populations (Graham, 2007), such as LGBTQ+. This is particularly important in light of the small number in the LGBTQ+ populations who at risk of being overlooked, especially in rural areas. Furthermore, an SDH perspective would consider not only ongoing, specified health concerns such as HIV/AIDS, but also broader health concerns of these populations.

Ontario was governed by the Liberal party during the time periods covered by the study. With a new Conservative government in Ontario as of 2018, a new approach to health care may emerge. As an indicator, one of its first acts of the Conservative government was to default to using major components of the previous sex education curriculum (CBC, 2018; Hauen, 2018). That curriculum was updated in 1998 and excludes content on sexual orientation and gender identity (McKenzie, 2015).

Regarding Ministry staff, most interviewees indicated some level of knowledge, sensitivity, and even support regarding LGBTQ+ health concerns, they also described the complexity of including this community in policy and funding due to ongoing systemic barriers (i.e., lack of knowledge or political will within MOHLTC) and poor-quality data. This is

exacerbated by the current absence of LGBTQ+-based health programming and the challenges, as one bureaucrat noted, in building communities in areas lacking supportive infrastructure (e.g., rural). Interviewees all seemed to have differing perspectives on their LHINs' level of LGBTQ+ community engagement; this speaks to the disjointedness of the structure toward this population across the province.

Regarding the LHINs, we found that there was very little on LGBTQ+ health except for Waterloo-Wellington and Toronto Central, who significantly increased the amount and quality of their LGBTQ+-specific content in the periods examined. Not surprisingly, these two LHINs had conducted strong community consultations, which improved their content. Among some LHINs that did not consult the community and had very little LGBTQ+ content, contact with community health care providers still managed to raise interesting SDH issues, such as housing and inclusion in family patient care. Given the lack of data and small numbers of LGBTQ+ in some of the regions, community consultation seems particularly important if policy-makers are to fully grasp their health situation.

As mentioned, Waterloo-Wellington LHIN stands out as a leader in community collaboration and advocacy for accessible and appropriate LGBTQ+ services. However, even this LHIN appears to be focused on *access* to services—an issue identified by Tjepkema (2008) a decade ago— without addressing structural barriers like poverty and social exclusion that are emerging in the literature (City of Toronto, 2013; Ross & Khanna, 2017). This absence may signal a limited understanding or other barriers for addressing broader SDH that need to be remedied.

The recognition of structural imbalances and the health consequences these produce must inform funding availability for LGBTQ+ health beyond HIV/AIDS containment. This includes a

deep-rooted recognition of health challenges premised on society's oppression of LGBTQ+ people that addresses "eco-social" approaches to health (Krieger, 2012) and contribute to our understanding of social determinates such as "minority stress" and "internalized homophobia" (Hatzenbuehler, 2009; Meyer, 2003). As well, an SDH approach that recognizes sexual orientation and gender and identity expression as a specific determinant cannot obscure the diversity of the LGBTQ+ community by subsuming it within an analysis of gender.

How population health and SDH perspectives could be operationalized in a policy context for the LGBTQ+ population is yet to be determined, but it is apparent that these health issues are not adequately reflected on the MOHLTC and most of the LHINs websites. Further research could undertake a literature scope of pressing health and wellbeing issues affecting the LGBTQ+ communities to provide more evidence for the recognition of sexual orientation and gender and identity expression as an SDH and the appropriate policy response.

The public websites examined are a key resource for public access to services and the policies that shape them. That said, one key limitation of this study is that it can be difficult to extrapolate what is actually happening at the level of community services and programs from the high-level analysis of a website. It is noteworthy that in some cases, the search of the LHIN websites yielded little or no content; yet, a broader Google search combining the name of the LHINs and some of the key words yielded additional LGBTQ+ content that one might have expected to see on the LHIN website. At the very least, this suggests some navigation problems in the design of the websites, which could be discouraging for those looking for information. When those looking for information are part of a vulnerable and stigmatized population, this barrier is particularly troublesome.

In the course of conducting this research, we realized that many of the key organizations, such as ASOs and Rainbow Health Ontario, which provide services to this community, are not funded by the LHINs. The process and rationale behind this might be an interesting area for further research on how LGBTQ+ health is addressed. More research on Rainbow Health Ontario's contribution to LGBTQ+ health equity might also be helpful to understand community needs and to develop an integrative means with the LHINs and the Ministry for moving forward. The improvement in the content of those website where the LHINs consulted the community, combined with ongoing concerns about the quality of the available quantitative data, underscore the importance of a fully representative consultation process.

Some LHINs noted the small number of LGBTQ+ in their regions and one commented the “uncomfortability” of discussing sexual orientation and gender and identity expression. These factors, combined with a disproportionate risk for serious health issues and small numbers of people concentrated in urban areas speak in favour of a population health approach with an SDH perspective, such as a provincial LGBTQ+ Health Strategy, to avoid overlooking a stigmatized community.

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Chapter Five: Perceptions and Experiences with Funding and Policymaking for LGBTQ+
Community Organizations

Abstract

LGBTQ+ populations are at a consistently higher risk for suicide, substance abuse, homelessness, and have limited or inappropriate access to health care and social services. However, issues such as HIV and mental health continue to dominate LGBTQ+ health research. Furthermore, literature on sexual orientation and gender identity as a social determinant of health (SDH) approach is extremely limited. Community-based agencies (or third-sector organizations) have argued that they are well positioned to provide culturally appropriate services and influence policy change through their relationships with funders and policy-makers. However, scholars and activists have also observed that government funding has moderated the politics of the LGBTQ+ movement.

This study examines the impact of a neoliberal policy—one that introduces competition for funding and pressure to professionalize and bureaucratize the environment—on the working conditions and precarity of a purposive sample of southern Ontario (Canada) organizations dealing with LGBTQ+ health issues, their funders, and other government policy makers. The possibilities and perils of a population-specific LGBTQ+ health strategy are also explored. Findings from semi-structured qualitative in-depth interviews with 20 community-based organization stakeholders, and government bureaucrats confirmed that the neoliberal policy environment pressures these organizations to professionalize and bureaucratize, while restricting political advocacy. Queer Liberation Theory's three central tenets of anti-assimilationism, solidarity across movements, and the political economy of queer health under neoliberalism are used to better understand the situation and possible futures for third-sector organizations within

the LGBTQ+ movement. This study proposes ways to reframe the discussion on LGBTQ+ health equity using the insights of Queer Liberation Theory.

Key Words: LGBTQ+, Queer Liberation Theory, Social Determinant of Health, Health Equity

Introduction

The North American LGBTQ+ community is at a significantly greater risk for suicide, substance use, (Kulick, Wernick, Woodford, & Renn, 2017; Pakula, Carpiano, Ratner, & Shoveller, 2016; Veale, Watson, Peter, & Saewyc, 2017), HIV (Centers for Disease Control and Prevention, 2015, Forsyth & Valdiserri, 2015; Public Health Agency of Canada, 2015) and homelessness (Abramovich, 2012, 2016) than other populations. The community also faces barriers accessing appropriate healthcare and social services (Lim, Brown, & Jones, 2013; MacDonnell & Daley, 2015; Mulé, McKenzie, & Khan, 2017; Obedin-Maliver et al., 2011; Tjepkema, 2008). Issues such as HIV and mental health disproportionately dominate LGBTQ+ health research (Mulé et al., 2009). At the same time, there is a fledgling discussion in the literature about turning attention to structural issues such as social stress and exclusion (Gahagan & Colpitts, 2017; Khan, Ilcisin, & Saxton, 2017; Krieger, 2012; Meyers, 2003; Steele et al., 2017; Zemman, Aranda, Sherriff, & Cocking, 2016) and housing and poverty (Blosnich et al., 2017; Emler, 2017; Ferlatte, Salway, Trussler, Oliffe, & Gilbert, 2018; Wade & Harper, 2017). The full extent of the health inequities experienced by the LGBTQ+ community in Canada is likely not fully understood, because national health surveys have restricted identity categories (Cahill & Makadon, 2017; Dharma & Bauer, 2017; Wolff, Wells, Ventura-DiPersia, Renson, & Grove, 2017).

Because of their connections to individuals and communities, community-based agencies (or third-sector organizations) are well situated to provide culturally appropriate services. Some also try to influence policy change through their relationships with government funders and policy makers, thereby attempting to address the LGBTQ+ population's health inequities at this mezzo level of intervention. Both activists and scholars, however, have expressed concern that

government funding policy has had the effect of moderating the politics and engagement of the LGBTQ+ movement (Evers, 2009, Kinsman, 1987; Tremblay, 2015). Others have raised the same concern, but in the context of professionalization of the third sector “as an industry” (Onyx, Armitage, Dalton, Melville, Casey, & Banks, 2010). This study uses Queer Liberation Theory, complemented by the concepts and language of the social determinants of health (SDH) framework, to examine the perceptions and experiences of selected LGBTQ+ community organizations with current funding and policy making mechanisms.

In addition, I was also interested in interviewees’ reflections on the idea of a national and/or provincial LGBTQ + population-specific health strategy, because a population health approach is well recognized as important and effective. Health Canada defines a population health approach “as a unifying force for the entire spectrum of health system interventions—from prevention and promotion to health protection, diagnosis, treatment and care—and integrates and balances action between them,” that focuses on “the interrelated conditions and factors that influence the health of populations” (PHAC, 2013, para. 1-2). Health Canada has been committed to population-specific health since 1997 for the development and implementation of policies and practices to “improve the health and well-being” of specific populations “over the life course” (PHAC, 2013, para. 1-2).

Theoretical Framework

Queer Liberation Theory

As an emerging theory, Queer Liberation Theory assumes that people hold diverse sexual orientations, gender identities and expressions, as well as sexual characteristics (i.e., intersex people) that extend beyond dominant heterosexual and cis-gendered concepts (Mulé, 2012). Queer Liberation Theory shares Queer Theory’s concept that sexuality is fluid, and does not

reject or judge essentialist identities (such as gay, lesbian, trans, etc.) Queer Liberation Theory strives to be a progressive, critical, sex-positive, liberationist perspective by focusing on three key concerns: anti-assimilationism, notions of solidarity across social movements, and the political economy of queerness, especially the impact of neoliberalism (Mulé, 2016).

Neoliberalism embodies market-oriented principles, such as competition, minimal regulation, personal responsibility, and warns of the hazards of the “nanny” state and the costs that it incurs (Harvey, 2009; Navarro, 2002).

For this research, I use a broad, simplified understanding of the third sector. Alcock (2010) identifies the interaction of three social entities: the state, the market, and civil society. Simply put, the “state” is the government and public sector, the “market” refers to for-profit businesses, and “civil society” denotes citizens collaborating on behalf of citizens (as opposed to on behalf of the other two sectors) (Alcock, 2010; La Forest, 2009; 2011).

The literature on the third sector identified and clarified a number of areas that I wanted to better understand regarding LGBTQ+ community organizations. As some scholars note, by funding the third sector, the government is able to offload its responsibilities in the name of community engagement, while hiding under the rhetoric of efficiency, cost-effectiveness, and accountability (Cain & Todd, 2008; Cunningham, 2010; Evans, Richmond, & Shields, 2005; Evers, 2009; La Forest, 2011; Mulé, 2011). In the quest for efficiency and cost-effectiveness, governments then tend to implement competition for funding among organizations and precarious short-term funding contracts (Cain, 2002; Cain & Todd, 2008; Guta et al., 2014), which negatively impact working conditions (Cain & Todd, 2008; Hall, Barr, Easwaramoorthy, Sokolowski, & Salamon, 2005). One participant in Cain and Todd’s (2008) study of HIV/AIDS social services in Canada laments the “loss of legacy” (p. 275) caused by insufficient funding

and high turnover rates among staff. In the quest for accountability, organizations become increasingly bureaucratized and professionalized, with an emphasis on “evidence-based” criteria for successful programming (Cain et al., 2014; Hastings, 2016). As the current research corroborates, the concern with this approach is that the third sector has become too professionalized (Lewis, 2012) and too closely mirrors government operations (Cain, 1997; Cain 2002; Cain & Todd, 2008; Cain et al., 2014; Guenter et al., 2005; Hastings, 2016). Thus, although third-sector organizations identified themselves as vehicles to enact community-oriented social policy and service provision, funding restrictions can limit their effectiveness in fulfilling community needs (Enjolras, 2009).

Methods

This qualitative study provides a critical policy analysis informed by Queer Liberation Theory’s understanding of neoliberalism. This use of a political economy perspective (i.e., the focus on neoliberalism) is a well-established approach in health policy analysis (Walt & Gilson, 1994).

Data are from semi-structured, in-depth interviews with key informants. I used snowball sampling (Babbie & Rubin, 2008) to identify a purposive sample of participants within the Greater Toronto and Hamilton Area. This geographic area was chosen because of the concentration of the LGBTQ+ population and to make the project manageable. The sampling process started with identifying MOHLTC staff based on their positions in the online organizational chart. These individuals, as well staff in the community organizations, recommended funders and policy makers who were in a position to speak knowledgeably about the issues under study. Seven bureaucrats from municipal and provincial levels of government agreed to participate. Bureaucrats at the federal level declined.

Although this study does not claim to provide a province-wide sample, I did seek out organizations based on specific criteria. From my standpoint and involvement in the community, I had witnessed underlying tensions among organizations, which I wanted to explore. Specifically, some in the community perceive that larger organizations are favoured with funding over smaller ones. Organizations targeting racialized LGBTQ+ communities also feel marginalized, both by funders and other community organizations. Thus, I ensured that organizations of various sizes and those working with racialized communities were included. Although I did not include any rural organizations, I did ensure to include some located outside of Toronto.

The specific health inequities faced by the LGBTQ+ community identified in the literature, combined with insights from the literature on the broader third sector allowed me to identify the important components for analysis and the relationships among these components (Ostrom, 2007). Thus, I formulated interview questions that address the impact of funding mechanisms on working conditions, the nature of voluntarism, and the process of bureaucratization in the organizations under study. I also asked interviewees about the pressure for evidence-based accountability as a way to discuss the professionalization of the organizations. By asking about participants' understanding of the SDH, I explore the perceived capacity of the third-sector to advocate for policies and provide services that grapple with the unique social determinants of queer health.

Finally, in the interest of looking to improving LGBTQ+ health, this research explores and analyzes the need for and possibility of an LGBTQ+ population-specific health strategy. My research questions stem from my personal experience as a queer person working within the community, my concern for addressing structural health inequities, and the lack of understanding

of queer issues in the SDH framework. To my knowledge, there is no literature on using this policy strategy for addressing LGBTQ+ health.

I conducted and analyzed 20, semi-structured, in-depth interviews with 13 community organization (CO) staff and seven policy-makers in the Greater Toronto and Hamilton Area that were involved in LGBTQ+ health portfolios over the course of 2017. Staff participants included both managerial (e.g., executive directors) and front-line program staff. These individuals are described as community organization participants (CO). Policy-makers and funders holding various positions within municipal and provincial governments were purposively chosen to respond to questions about the various sources of funding that community organizations access. These individuals are described as “bureaucrats.” Despite repeated invitations, federal funders did not make themselves available.

Interviews were transcribed verbatim by a professional transcriptionist. I checked the transcripts for accuracy and I manually coded the text thematically. Thematic coding proceeded using a pre-determined coding framework that emerged from the literature, rather than allowing for themes to emerge from the interviews. Thus, the following findings are organized based on the interview questions,

Findings

Unstable Funding and Precarious Employment

Both front-line workers and a few managers described high turnover rates across the sector. One manager (CO 2) noted that “every time you go to a meeting [with other community organizations] ... a quarter of the group is new people. And that’s really high.” This high turnover negatively impacts both retention of staff and community-building. Another community organization participant commented, “Even though I’m just coming up on my two-year

anniversary, I'm an old-timer now" (CO10). Another pointed out the fragile and fragmented nature of community relations and development:

You've been in a relationship with this person at that organization, and then that person moved on, and ...the new person in that position needs to catch up with all of the science and the research, and then connect to all of the services in the community and try and reinvent that for themselves. (CO12)

One of the reasons for the high turnover of staff is the precarity of funding coupled with the continuous pressure to renew it:

It's contract, so we end in June, June 30th, unless we renew our funding, because it's a three-year program...funded by the City of Toronto.... We find out actually the day after tomorrow.... Yes. So, it's been kind of like, I think everyone's a bit worried, because it's a lot more uncertain. (CO 5)

Indeed, two of the community interviewees are no longer in their positions. Managers and executive directors complained of cutbacks in funding resulting in having to dismiss staff. In one case, over 10% of staff had to be laid off or were not rehired.

A related concern is that funding decisions often arrive at the last minute or even past the deadline for the funding contract, which increases stress. As one executive director recounts:

It's now almost May and our project ended March 31st, and we still don't have cheques in our account. And we don't have any MOUs [memorandum of understanding] signed, either. But they gave us a letter saying, you know, if you need a letter from us to confirm funding, we can certainly do that, and you can go to the bank and get a loan. So, you know, those kinds of policies are ridiculous. (CO 6)

Organizations reported not only having to renew funding annually or more frequently but having to compete with similar agencies for limited funds. This was complicated further by often having to work with multiple funders. The same community participant speaks to the complexities of the funding dynamics:

We have four full-time permanent positions that are funded by the AIDS Bureau; we have one part-time permanent position that's funded by the AIDS Bureau. So that's core funding. And then we have project-based funding with the city, which has two full-time positions and one-part time position. And they're three-year contracts, usually. And again, every three years, we have to enter a competition to see if we get approved or not. The Public Health Agency of Canada [has] now funded for two full-time positions and one part-time honorarium-based position.... (CO 6)

Some participants noted that the competitive process seems to disadvantage such organizations with few staff that serve racialized communities. Another community organization staff member highlights disparities between urban and rural organizations: “Part of what I notice in Ontario is that a lot of the funding for ... LGBT health initiatives in particular, seems to come to Toronto or other big cities” (CO 8). They went on to attribute funding problems to poor health outcomes in these regions: “When I think about the health disparities we see in the province, the health outcomes in northeastern Ontario are the worst and there’s LGBT people who live up there, but are there resources to follow that? Probably not” (CO 8).

The Role of Volunteers

One of the workarounds to the problems of precarity and underfunding has been to use volunteers. As another community staff member noted, “We, as an organization that was

...founded as a collection of volunteers that were just trying to help people who were dying [during the AIDS crisis], and nothing was known about how to support these people” (CO 2).

Indeed, a number of the interviewees had started as volunteers. They volunteered to help organizations stay connected to the community, provide an insider’s perspective on needs, lend credibility to the organization, while, in turn, having a safe way to “self-identify” (CO 2):

So, many of my programs are gay men’s type programming. And so many gay, bi, queer men volunteer in these programs because they are peers and they are directly connected to wanting to support people in community that are their peers, their friends, their lovers, their family. And so, they do everything for my department from outreach, education workshops, co-facilitating groups. Sometimes some of our groups are facilitated only by volunteers. (CO 2)

To quantify the value of voluntary labour, one organization calculated that volunteer work annually equates to 12 full-time staff. While widespread volunteering may be symptomatic of underfunding, it also suggests that volunteer recruitment and retention programs are successful, enabling organizations to stay afloat and connected to their communities:

One of the things we’ve recognized over the last number of years is that they are human resources as well. So, you need to invest in your volunteers which means making sure that they feel valued. Providing supervision. Ensuring that they are trained. Ensuring that they are kept up-to-date with the latest developments because in many cases they are the face of the agency out in the community. Our retention rates are really good, which is actually a great thing because they [volunteers] actually feel like they have opportunities to move [up] within the organization. (CO 1)

Challenges to Doing Advocacy Work

Connectedness to the community does not necessarily translate into an ability for staff to engage in advocacy and social movement activities. One community organization staff member points out that:

Some of the advocacy that the AIDS community, HIV community have done in the past, which is take a position on something and then get public about it. Like, that doesn't really happen in Ontario as far as I can tell. Because nobody wants to mess with their funding. But that does happen federally. Organizations, you know, do postcard campaigns, they sign petitions, this, that, and the other thing.... We can't do much more than that. ...But if you're outside of Toronto, AIDS Action Now really doesn't give a shit about you. And frankly, neither do the Toronto organizations. So, like, you don't have that same advocacy voice. (CO 13)

Another interview (CO 10) echoes the challenges of doing advocacy work within the restricted parameters set by the government for funded organizations, especially in relationship to progressive politics:

I've always been a guy who criticizes the way that not-for-profits can sometimes co-opt social justice movements and water them down ... and yet, I know so many people with really radical politics who work inside of these [organizations], and I think that it's valuable. First of all, the work we do needs to happen. ... And then also, it puts me in a good position to do some of the extracurricular activist work. It makes a lot of inroads and makes it easier to do LGBT organizing outside of this system, as well as inside of it. (CO 10)

On the other hand, although LGBTQ+ advocacy may be limited in scope in third-sector organizations, CO 8 indicates the value of having politically driven staff is their connectedness to key stakeholders from both inside and outside of the organization. CO 8 also reflected on how the winning of civil rights (such as the right to marry) can sometimes obscure the larger structural issues: “One of the challenges ... is people thinking, ‘oh, you can get married, what’s the big deal? What else do you need?’ ... Without understanding the determinants of health pieces around that” (CO 8).

Participants discussed the tensions between one-on-one advocacy for individuals in their communities and advocating to address systemic, structural problems: One community participant noted: “I think we do advocacy really well on an individual level, not a system [level]...” (CO 7). Indeed, one bureaucrat confirmed that “the objective of the funding is really to address behavioural” issues through individual interventions (BU 5). However, community participants clearly identified social exclusion and housing as salient problems:

Whether you're HIV positive and/or LGBT identified, there's also social exclusion, right? And trying to find affordable housing.... And there's advocacy within that, too. So, if someone gets kicked out of a shelter, for example, for whatever reason, then we actually step in and kind of explore and mediate that situation to see what happened.... And we'll also sort of play the mediation role, as well, in terms of following up to make sure things are okay. (CO 6)

Some community participants, however, could point to successful efforts at dealing with structural inequities, for example, access to housing, even though such issues are technically outside the mandate of the organization:

Salvation Army is pretty much the big boss around housing in the region. They get most of the contracts in the region... So, they're just a massive player in housing. And to get it on their radar that they need to be considering some of the unique housing issues faced by transgender communities, individuals, and by transgender women specifically, was really a coup. So, getting trans women included in a project proposal that was funded, and then having dedicated housing subsidies for trans women [was great]. (CO 13)

In contrast, some bureaucrats said that "The SDH are a big part of what we do," (BU 1), noting that "the research clearly shows [the importance of SDH] and it's interwoven throughout our HIV Strategy ... that there really are social drivers to HIV" (BU 7).

Another concurred:

One of the underlying frameworks of all the funding is, of course, that they need to be addressing the social determinants of health, right? And our priority populations, and also funding objectives, were all developed—actually, based on—well, those social determinants of health that primarily affect MSM, right? Or LGBTQ+. (BU 5)

Impacts of Evidence-based Programming and Evaluation

Another factor working against organizations taking on the SDH is the requirement, often tied to funding, for evidence-based programming and evaluation. Effective community development approaches that are compatible with an SDH approach are also labour-intensive and resource-consuming. One participant pointed out that the problem is not necessarily with the evidence-based evaluation requirement, but rather with the type of evidence required:

I think it should be more qualitative. It shouldn't be about, you know, checking off how many people we've seen. We should be demonstrating value for our money, and ... we shouldn't be doing the same thing over and over again if the environment has changed.

We should be reflecting and questioning and managing change. And we should be gathering evidence. (CO 9)

Another participant illuminates the predicament with the following example:

If I ran a testing event and we had ten guys come out, I would go to my supervisor and not be sure how to present that. It's like, "Did we only get 10 guys?" or, "Hurray, we got 10 guys!" And I found that the way I presented it seemed to have more of an impact on how my management received it than anything, right? Like, if I went in and I said, "Wow, we got 10!" then everyone was, like, "Yay!" (CO 10)

Another participant agreed it is problematic to have to justify backing up the need for programming for a relatively small number of people, for example, queer and trans women:

I would love to do more work around [community withheld] women and the queer women's community, because I think that's where... there's a lack of funding because funders don't see queer women as at high risk for HIV and Hepatitis C. The numbers are not there. But the need is there. (CO 6)

Participants discussed other methodological dilemmas this way:

It's enormously frustrating, given what we know about syndemics and the impact of these various issues on the populations most at risk for HIV... As much as we need to take a ... comprehensive approach, they [the funders] don't understand how to link work on syndemics with reducing risk with individuals [in a way] that can be measured. So that's just hugely disappointing.... We know what we have to do, and then they tell us, well, actually, let's go back to doing [the same old] stuff, right? Really, just shocking and disturbing that that's the position taken by the [funder] at this point in history. (CO 10)

Another hurdle to evidence-based evaluation research and grant writing is community organizations' inadequate capacity and resources (Flicker et al., 2009). Smaller organizations, in particular, felt it was hard to compete with larger organizations that were more likely to have research capacity:

I will put in over a full—probably two full weeks of work to write an application. You know, it is a long process, and lots of weekends. If I was trying to run programming at the same time, front line, the service users would be suffering. I would have to cancel groups. I would have to do a lot. And a lot of us *do* work weekends and volunteer our time because we care about the work, and there's just not enough hours in the day. (CO 2)

Municipal bureaucrats also recognize that funders' increased demand for so-called “evidence-based” approaches as a rising tension inherent to the professionalization of services. One funder spoke about the challenge for racialized, ethno-specific organizations within the last 10 years, and especially over the past three-four years, to constantly have to apply for funding for their mainstream programming using “evidenced-based approaches” without adequate resources to accommodate this shift in the process (BU 5). Similar feedback has come from smaller organizations that lack the research positions more common at their larger counterparts (BU 5).

One interviewee points out the additional challenge of parsing the sometimes “inaccessible” language of the evidence-based reporting requirements: “Sometimes, it's just a guessing [game]. Like, “All right, so I think this is what they want. I'm not sure if they want a stat here.” (CO 4)

Despite the challenges posed by the evidence-based approach to funding, bureaucrats felt that, overall, the requirement for evidence is necessary: “It's really important. We try to use it for

every decision, really. Whether it's published literature or a feedback loop, like what's worked before." (BU 6). The emphasis on evidence has also denoted Ontario as "a leader in developing evidence-based policy," with outstanding researchers (BU 2). There is also funding available through "the Health Systems Research Fund [that] does evidence-based policy, as well as develop evidence to support key policy areas" (BU 2).

Bureaucrats recognized other challenges to using an evidence-based approach in that the evidence must "then be translatable and adaptable to the local context" (BU 7):

I think in the early days a lot of community responses were really based on grassroots' responses. But I think lately ... there's a big shift into requiring, actually, them to be using evidence-based approaches, or even finding evidence-based interventions, actually. ... There's a lot of pushback, sometimes, from the community. Because ... to be asking them to start evaluating programs is sort of taking away their time from doing service delivery. (BU 5)

While policy-makers/funders recognize the importance of evidence, they are also keenly aware of the influence of the inevitable politics associated with policy making, evidence-based or otherwise:

Sometimes we are very careful when we're taking forward, say, harm reduction reports. Is this the right time? Is it an election year? ... So, we're very careful in what we are supporting... It may not be that management says no', but they're saying, 'not right now'. And then it takes months or years longer. So, things do move slowly in a municipality. Very slowly. (BU 6)

Contradictory Views on Policy and Funding Consultations Between Organizations and Government

The government funders (federal, provincial, and municipal) of the agencies under study often engage community organizations in consultations to influence the direction of policy frameworks. Community organizations are keenly aware that such frameworks may in turn influence funding priorities. Third-sector organizations' staff, with some exceptions, held fairly negative views of this consultation process and outcomes. For example, CO 6 described the consultation process this way:

Sometimes it is tokenistic, or sometimes it feels tokenistic. But eventually, at some point, you know, down the line, before their term ends in government, then they would listen, right? [However], if you're working with departments, they actually respond relatively quickly, and they're getting better at being inclusive and not looking at us as tokens, but rather people with opinions and informed opinions, too. So, they're getting better. (CO 6)

Others felt consultation was a "waste of time" (CO 9) at worst, and that this was the predominant feeling throughout the organization. One interviewee described the frustration of consulting on needed supports and services for which there is no government allocation: "The Minister had nice things to say but then ...also ended by saying there's no new money. Which is like, there's been no new money for a dozen years under this portfolio." (CO 1)

Another interviewee, who felt disempowered with recent interactions with the funder, expressed frustration in this way:

I would say that this is probably one of the darkest periods in my career in terms of dealing with bureaucrats. Politically, obviously, we're in much better shape than we were a year and a half ago. But it's been counterintuitive, because the bureaucrats have been

really nasty. Unnecessarily so, I think. And so, it's been bizarre, because here we have, you know, a vastly improved minister and government in terms of the issues that we work on, but the bureaucrats have been acting like we don't know what we're doing and that they have to tell us how to cross our *t*'s and dot our *i*'s, and it's been really frustrating ... it's very, very hard to do advocacy where bureaucrats don't end up feeling offended, and then taking action to withdraw support from you, or to not trust you, or to not share information with you, or whatever. And that happens all the time. (CO 9)

Another expressed similar concerns, but ultimately felt it was personalities and personal politics, that got in the way of genuine consultation. They argued that it was easier to advocate for funding to meet community needs with some funders than with others. Some experiences were even adversarial:

So, I feel like it's easier for us to do advocacy with an organization like [funder x] than it is to do advocacy with [funder y]. And so, it's harder to sort of challenge things. ... So, somebody says we should be doing this, and [the funder] said, 'No, not going to happen.' And it's kind of the end of the conversation. And so, then people sit around—like, and they stew, right? But they also realize that, like, they're not going to be ... the shit-disturber that raises this again, because you're cut down publicly, and told it's just not going to happen. And you sort of get the stink eye that says, like, you're on my bad side now. (CO 13)

Conversely, CO 8 described having positive interactions with people in various levels of government who were trying to lend their insight into the organization. These interactions are founded on

...really strong relationships where people can send us information so that we don't miss anything, and it's not just us getting the newspapers about what's coming up in government people saying 'here's something you might want to insert yourself in or try to' has been really helpful. And of course, that may or may not result in anything, but if we don't at least send a letter, definitely nothing is going to happen ... or if we don't have a conversation. (CO 8)

In turn, policy-makers' viewpoints on their relationships with the organizations tended to be consistently positive, emphasizing regular and ongoing consultation, and the importance of the community's input and expertise. One policy maker noted that "you need engagement, you need evidence-based policy, you need to partner with community groups and those on the ground; you also need to partner with researchers". (BU 2)

Another bureaucrat characterized the relationship this way:

I think it's really that there isn't an us-and-them anymore But there's clearly an us-and-them in terms of we have a very specific role to play. We're here to support the government to make an informed decision, and then we're tireless implementers of that direction And that's—you know, I think at some point there's a significant amount of education that has to go on out in the real world with those stakeholders about well, what do we do and in what ways can we be your partner and in what ways will we never really be your partner? (BU 3)

Or as another policy maker put it, bureaucrats are "no longer the gray or blue-suited mandarins" (BU 4) advising the elected officials behind closed doors. Stakeholders are encouraged to engage decision-makers on relevant topics, adding transparency and accountability to the process.

Policy-makers were quick to praise the formal political process as a source of consultation and advocacy. One policy-maker notes that “I’d say most of the things we see come through MPP letters. That does not preclude groups from directly contacting us...” (BU 2).

Another noted the more informal ways to engage: “And sometimes it's when I'm up, out about in the community, of course, then there's always interaction, certainly, with members of the community if I do run into them in public” (BU 5).

The Need for an LGBTQ+ Health Strategy?

Currently, there is no Ontario or national policy on LGBTQ+ health. This research explores why that is the case and whether such a strategy would be helpful. All but two community participants felt that an LGBTQ+ health strategy was needed. Those that did not, felt that LGBTQ+ concerns should be reflected in all health policy.

One community organization staff member notes that very little policy work is focused on LGBTQ+ health, which was especially troubling considering the health inequities the community faces (CO 8). Another highlighted that he has been advocating for a LGBTQ+ health strategy for years. He felt the policy making process was not clear. “What is the framework for LGBT health and how does that get introduced into policy? How does that influence different jurisdictions around things that we need to consider and fund for LGBT health?” (CO 13)

Community interviewees were unanimous in their view that existing services are inadequate. Some were concerned that the Canadian government has only taken symbolic and grossly inadequate measures to ameliorate one of the most endemic SDH problems faced by the LGBTQ+ community: poverty and homelessness, particularly among trans people and youth.

Participants identified many other gaps that need to be addressed including the following: decriminalization of HIV non-disclosure to sexual partners; human papilloma virus vaccinations

to address higher rates of cancers, universal pharmaceutical drug coverage (including PrEP), culturally competent sexual health and mental health services; services for the Trans community; as well as resources to develop an “LGBTQ+ lens” on structural issues such as housing, poverty, and social exclusion. One respondent suggested that there should be an exclusively LGBTQ+-specific community health centre (presumably one that is independent from hospital health centres) which includes LGBTQ+ populations as the priority groups served.

Another community participant echoed others’ concerns on the need for a cross-jurisdictional strategy: “And I think that a national health policy needs to provide guidance and leadership to provincial and territorial health policies. But they need to [also] influence, you know, local or regional LGBT health policies” (CO 13). Another community participant pointed out that “... the syndemic considerations of mental health, and the ways that those affect the choice-making that we engage in around sexual health need to be really acknowledged at a funder level, and at a federal funder level” (CO 2).

Other community interviewees, however, disagreed: “I don’t know that a single health policy would be useful or adequate” precisely because of the different jurisdictions for health (CO 6). CO 8 expressed the concern that “when you start looking at specific health policies for specific communities... we continue to create division.”

Bureaucrats were not aware of an existing or emerging LGBTQ+ health strategy. In fact, many were at a loss as to how to answer the question about whether such a policy is needed or would be beneficial. When this question was explored further, some expressed interest and enthusiasm for such a policy, but the dominant response was that the current approach is to embed an awareness of LGBTQ+ health issues across all policies. For example, one policy maker discussed some of his recent work:

One of the key components of the work that we've done, we've spent about two years travelling around the province with consultations and one of the things we've heard that's specifically relevant to the LGBT community is the challenges in getting senior services, and specifically dementia services, that are tailored to the queer community. And so, we've heard horror stories, really, of people who live their lives out and as openly gay members of society, and then when they're in a long-term care home or a retirement home, are having to go back into the closet. And that's not acceptable to us, and so we've made sure that very much we've put an equity lens, and especially as it relates to the LGBT community and the work that we've done on the strategy. (BU 3)

Discussion

The perceptions and experiences of the LGBTQ+ community organizations in this study regarding funding and policy-making mechanisms largely concurs with the findings in the literature, with the important exception of notions of professionalism. This discussion explores the application of Queer Liberation Theory's tenets to the findings of this research. As noted, these tenets are anti-assimilationism, solidarity across movements, and political economy as it relates to queer communities, in this case, the impact of neoliberalism in particular. Also implicit in Queer Liberation Theory is the notion that strategies for improving the health equity of the community as a whole must be community-driven. Just as Queer Liberation Theory is under development, so too, I would argue, is the development of the discussion of health equity from a liberationist perspective. Thus, I discuss the themes raised by this research from the viewpoint that these discussions have only just begun. I argue that the tenets of Queer Liberation Theory help to shed new political light on the structural impetus behind the inequities facing the queer community and the discrimination that these perpetuate.

Precarious Working Conditions

This research shows how unstable funding and precarious employment impact working conditions and ultimately, the operation of the organization. For example, participants discussed high turn-over rates and a reliance on volunteer labour (Laforest, 2011). In one organization, volunteers played a crucial role in the day-to-day operations. Participants also described, however, the value of volunteerism for staying connected with the community and creating employment and learning opportunities. A Queer Liberation Theory perspective, with its understanding of the economics and power dynamics of neoliberalism, could help to expose the guise of offloading services in the name of community engagement (Cain & Todd, 2008; Cunningham, 2010; Evans, Richmond, & Shields, 2005; Evers, 2009; La Forest, 2011). A better understanding of neoliberalism might help the community respond more effectively. For example, community organizations may learn to start to take a closer look at the research and activism around welfare states and their differing experiences under neoliberalism, that is, not all countries have reduced their social welfare protections to the same extent (Bakker, 2007). An understanding of neoliberalism is intertwined with another tenet of Queer Liberation Theory, which is creating solidarity across movements. For example, veterans, once considered a “deserving” group for government funding, now face the financial insecurities created by a neoliberal paradigm (Brewster, 2017) which highlights the socioeconomic drivers behind cuts and changes to funding and services.

Bureaucratization, Professionalization and Evidence-based Programming and Evaluation

Community participants did not express an understanding of the negative aspects of professionalization, as described in the literature (Onyx et al., 2010). They understood “professionalism” as using good practices and treating clients with respect, rather than as a

distancing from their communities. They were, however, keenly aware of the related issue of the impact of requirements for so-called evidence-based evaluation. No individuals quarreled with the need for evidence, but a number expressed strong opinions about how well the required “evidence” by funders reflected the reality they deal with. Indeed, even some of the bureaucrats who were demanding the evidence acknowledged the political challenges of collecting and implementing evidence, as in the example offered by one bureaucrat regarding harm reduction. Within a Queer Liberation perspective, the push for evidence and the selective use of evidence (e.g., regarding harm reduction as discussed in the findings) can be better understood in the context of a neoliberal, frugal welfare state. It is a means of seeking quantitative justification for service provision aligned with funding restrictions over qualitative effectiveness, often resulting in band-aid solutions. Indeed, the neoliberal paradigm challenges the very democracy of civil society if we follow Alcock’s (2010) reasoning that altruism is the guiding principle upon which civil society rests. In short, “citizens” have become “consumers” and “taxpayers” (Enjolras, 2009).

Advocacy and Solidarity Across Movements

Also described in the literature is the impact of government funding on limiting supports and opportunities for community (as opposed to individual) advocacy. By community advocacy, I am referring to advocating for the betterment of the entire community rather than for individuals. Advocacy issues were largely discussed in the context of a discussion of the SDH framework. Part of the motivation behind this research was to explore if participants in the movement still had liberationist viewpoints that understand socioeconomic structures and the inequities they can create. I was pleased at the depth and breadth of most participants’ understanding and articulation of the structural impetus behind health inequities. Yet, I was not surprised when

many confirmed what the restrictions on their community advocacy efforts were due to lack of funding and increasing bureaucratization of their organizations, as discussed in the literature (Cain et al., 2014; Hastings, 2016). As noted in the findings, participants reported that they sometimes found creative ways to get around these restrictions, for example, regarding advocacy on housing that is outside the scope of their mandate. This creativity reflects an understanding of the importance of community advocacy and also showed an awareness and comprehension of structural health inequities. On this issue of the SDH framework, bureaucrats and community participants shared a conceptual understanding, but had different viewpoints on whether this framework was actually being implemented. Thus, Queer Liberation Theory may be useful in building on this structural understanding, especially regarding the need for solidarity across movements to resist transformative neoliberalism's impact.

Consultation for Policy Making

One of the most striking findings of this research was the contrast between how community groups and bureaucrats understood and appreciated the role and effectiveness of consultation. Bureaucrats recognized the value of community consultation and tended to think that they did extensive consultation. On the other hand, community organizations' participants' descriptions of the quality of consultation process ranged from "great" to "my darkest days". The overwhelming feeling among community participants on their interaction with policy-makers/funders was that consultation was not the source of policy change and certainly not a route to enhanced funding. As such, this research also reflects concerns raised in the literature that the consultation process itself exemplifies governmental control and implementation of the neoliberal principles of efficiency, effectiveness, and accountability cloaked as community engagement (Cain & Todd, 2008; Cunningham, 2010; Evans, Richmond, & Shields, 2005;

Evers, 2009; La Forest, 2011). Again, active work in the community on refining an understanding of neoliberalism may be helpful in strategizing ways to deal with this reality. For example, Queer Liberation Theory could help clarify the reasons behind the apparent futility of consultation that could lead to new avenues for community engagement with government or social action to improve the social safety net across society.

LGBTQ+ Health Strategy

With few exceptions, community participants supported the idea of an LGBTQ+ Health Strategy. The question of an LGBTQ+ health strategy illustrates the contradictions faced by the queer community and how Queer Liberation Theory can contribute to the community's thinking about a strategy. Given the internal diversity within the LGBTQ+ community, there are probably more questions than answers about a health strategy at this point. I argue that a Queer Liberation perspective could help to frame these questions by applying its three tenets. For example, since Queer Liberation Theory emphasizes a distinct queer culture and anti-assimilationism, does it follow that there should be a distinct health strategy that is culturally appropriate to the queer community? Certainly, from a neoliberal perspective, it is more "efficient" to embed a queer perspective across policies and programs. However, would embedding a queer lens in all health policy and programs, as advocated by the government, assimilate and possibly obscure queer health issues? At the same time, it is imperative to consider whether a distinct LGBTQ+ health strategy might serve to isolate or ghettoize the community and promote an "us and them" mentality, rather than solidarity.

Also, there are diverse communities within the LGBTQ+ community. Would a strategy, particularly if it were initiated by governments, tend to homogenize the identities and needs of the various players in the community? Similarly, these results indicate perceived disparities

between community organizations that serve racialized groups and northern, remote, and rural communities and larger organizations in the cities. As such, Queer Liberation Theory could help develop a deeper understanding of the complicating and contradictory impacts of racialization, Indigenous culture, gender, geography, disability, etc. with a view to focusing on unity and equity.

My thinking behind developing a strategy is not that it alone will change socioeconomic structures and neoliberal ideology—although increased funding and better services might be a welcome outcome. Within a Queer Liberation Theory framework, the goals of working on such a strategy would be less the strategy itself and more about building the movement. Developing an LGBTQ+ health strategy could raise awareness of health issues beyond HIV/AIDS, sexually transmitted infections, and mental health and beyond lifestyle and personal responsibility choices to challenge heteronormativity. This includes challenging the SDH framework's heteronormative understanding of sexuality as a social determinant. The process of developing a strategy could be used to galvanize the community in a way that mainstreams health equity as an approach to LGBTQ+ health, while recognizing a distinct queer culture. Thus, using a Queer Liberation Theory framework could help to expose the complexity and dichotomies of the policy-making and social change processes by illuminating the risks of assimilationism and emphasizing that it is health equity that needs to be mainstreamed, not queer culture. As such, the awareness of anti-assimilationism within the health care realm might better help the community to resist the pressure to become “acceptable” in order to pursue services and other aspects of health equity. Furthermore, when health equity for everyone becomes part of the discussion, perhaps even the focus of the discussion, this creates opportunities for cross-movement solidarity that have a better chance of effecting structural change through strength in numbers.

Limitations and Areas for Further Research

As a qualitative study, this research cannot be representative of the entire LGBTQ+ health sector in the Greater Toronto and Hamilton Area or Ontario, nor does it purport to be. The current level of understanding of the issues invites both quantitative studies that capture all organizations, such as surveys, and qualitative approaches such as community forums as methods for future research. Although racialized groups were specifically included in the organizations studied, much more research is needed on the issues facing these queer communities, as well as the experiences of the many other minority cultures and those in northern, remote, and rural areas. For example, the fact the racialized organizations in this study felt disadvantaged with regard to funding could prompt investigation into the experiences of similar community-based organizations to explore why this might be the case.

The lack of research in these areas, along with the developing insights from Queer Liberation Theory, bring forth new opportunities for research, community development, and for changing how we think about LGBTQ+ health equity and approaches to advocacy and service delivery. With the change in government in Ontario at the time of writing, this study is timely. This need to understand neoliberalism and the real meaning of “finding efficiencies” to fund services, as proposed by the new Conservative government, is even more important in Ontario now that we have an openly neoliberal and thinly veiled anti-queer government.

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Chapter Six: Conclusion: Growing the Seeds of Queer Liberation

Introduction

This concluding chapter reviews the key findings of two content analyses and 20 interviews with community organizations and health bureaucrats. The chapter describes how the content of each of the studies relates to one another and to the larger question of structural approaches to LGBTQ+ health equity. I also address the limitations of this research, some possible ways to address them in future research, as well as provide some suggestions for additional research. Finally, I explore whether an LGBTQ+ Health Strategy is an appropriate policy response, particularly from the viewpoint of the LGBTQ+ community.

Main Findings

In Chapter 2, I explain Queer Liberation Theory as it applies to my research. Because Queer Liberation Theory is still under development, the key contribution of Chapter 2 is to articulate three pillars of the theory: anti-assimilationism, solidarity across movements, and political economy. My research focused primarily on the third pillar, political economy, specifically the impact of neoliberalism to the organizations under study. I hope that all the articulation of these pillars will aid in the further development of Queer Liberation Theory, both for scholarship and as a practical tool to shape social policy and invigorate a structural analysis in the movement from the bottom up.

Chapter 3 asks if the emergence of HIV/AIDS among the gay male population was a “defining moment” for the Canadian gay liberation movement. The study clearly confirms that it was. Despite advances in the prevention and treatment of HIV over the past four decades, however, the current literature suggests that LGBTQ+ health issues have only recently been considered outside of a medicalized HIV/AIDS framework. Chapter 3 is also the source of an

overarching question of the research: to examine and understand why the gay liberation movement of the 1970s and 1980s, seemed to me to approach political issues with a structural analysis that is no longer prevalent. Because this is too large a question for this dissertation, I decided to explore the changing (or not so changing) policy and programming landscape of LGBTQ+ health to understand whether there are any remnants of a structural analysis, such as the social determinants of health (SDH), in the movement. I was pleased to find that there is. Many of the staff I interviewed showed a good understanding of SDH. Furthermore, organizations often went above and beyond their mandates to work on SDH issues (e.g., housing issues) and community building.

As shown in Chapter 4, however, the current literature on sexual orientation, gender identity, and expression and SDH shows that structural approaches to the understanding of LGBTQ+ health inequity starting to expand. Even the structural SDH framework has, until recently, missed the mark on recognizing and understanding sexual orientation and gender and identity expression as an SDH, sometimes conflating gender and sexual orientation as equivalent or identical social determinants (Mikkonen & Raphael, 2010).

The findings from the content analyses of the Ministry of Health and Long-Term Care's (MOHLTC) and Local Health Integration Networks' (LHINs) websites discussed in Chapter 4 show just how marginalized LGBTQ+ health and health inequities are in the current policy arena—at least as they articulated on these government websites in Ontario. Despite the perception that the community has experienced increasingly progressive change, this study shows that, as represented in their online content, the LHINs and the MOHLTC pay mere lip service to the importance of LGBTQ+ health. Despite a general (though sometimes cursory) recognition of this population, online content on policies and programs either doesn't exist or is

one-dimensional in that it continues to emphasize a disease focus on HIV/AIDS and sexually transmitted infections. Further, until almost a decade ago, even the Toronto Central LHIN—which serves Canada’s largest and most diverse city—lacked substantive content and emphasis on LGBTQ+ health. Moreover, the findings of this research show very little change in the trajectory of this situation over the seven years between the first and second time period of the study. The fact that HIV/AIDS has dominated and continues to dominate the discussions about LGBTQ+ health means that we don’t yet have a full understanding of the broad range of health inequities that this diverse community faces. For example, there is still a dearth of research on the extent and impact of poverty in the LGBTQ+ community.

Despite the shortcomings of the SDH framework regarding LGBTQ+ health, the language of SDH proved to be a useful tool for discussing structural health inequities with both the bureaucrats interviewed and the community organizations in this study. Chapter 5 demonstrates that most bureaucrats showed an intellectual understanding of SDH. Community members, on the other hand, showed both an intellectual and practical understanding. This is perhaps best illustrated by the profound difference in the perceptions and experiences of those involved in the Ministry consultation process. The interviews with Ministry bureaucrats showed they had a much more positive assessment of these interactions than did many community participants. For the most part, community organizations felt consultations were tokenistic because they took place in an environment where there has been no “new money” or change in policy direction for decades. As such, the organizations’ ability to address the SDH is restricted by the dominance of a medicalized HIV/AIDS framework and neoliberal restrictions on how and how well these organizations are funded. However, I was pleasantly surprised by the wealth of knowledge and experience of SDH among community organizations, suggesting that a structural

analysis of health inequities still exists. Furthermore, this research suggests that consultations do offer some advantages. For example, Chapter 4 shows that when the LHINs consulted the community, the amount and quality of the LGBTQ+-specific content greatly improved on the LHIN websites.

LGBTQ+ Health Strategy

The policy response to this situation that I proposed to research participants is to develop an LGBTQ+ provincial and/or federal Health Strategy that ideally, would use an SDH framework. In Chapter 5, the findings show that while bureaucrats were generally sympathetic to the possibility, they were not optimistic about its chances in the current policy and fiscal environment. Community organizations, for the most part, were more enthusiastic about the idea of a population-specific strategy, though one person raised the possibility that it could be divisive. For example, how could the community ensure that a strategy would not just reproduce the divisions within the community: racialized groups vs. non-racialized, urban vs. rural, large organizations vs. small? Another concern is how well a government policy strategy could achieve Queer Liberation Theory's ideal of promoting inclusion while resisting *both* mainstreaming and "othering" within the diverse LGBTQ+ community and the larger society. These concerns point to a creative tension in Queer Liberation Theory. That is, the commitment to maintaining and a developing a distinct Queer culture, while building solidarity across movements of marginalized groups. This ideal of a "distinct" culture could play into the more divisive aspects of "identity politics" or suggest a judgement that Queer culture is somehow superior to others.

I argue that this tension should be explored and exploited in the rebuilding of a Queer liberation movement generally, and in the development of an LGBTQ+ Health Strategy

specifically. Indeed, this research shows that a strong foundation of structural analysis on which to start this rebuilding exists within the community organizations. Thus, as noted in Chapter 5, the primary purpose of such a strategy could be to galvanize a social-movement response from the Queer community to addressing ongoing health inequities, particularly expanding beyond judgmental approaches to lifestyle issues and sexually transmitted infections.

Although it is unrealistic to expect a government policy to transform the political economy of our society, the process of developing the strategy could contribute to transforming the community's understanding and action towards health inequities. Indeed, organizations have already seen indications that the funding focus on HIV/AIDS is beginning to shift to include more sexually transmitted infections. There are concerns in the community that the government will take the move to change funding priorities as an opportunity to reduce overall funding, rather than could create possibilities for addressing the health issues of all the people included in LGBTQ+. Reconfiguring funding for HIV/AIDS, based on the latest medical/scientific advances, is a welcome development. However, any reconfiguration must be balanced with addressing LGBTQ+ health needs within a broader, structural understanding of the issues. The development of an LGBTQ+ Health Strategy could potentially inform the direction of this shift toward a more comprehensive and equitable approach to LGBTQ+ health. I argue that Queer Liberation Theory is a very promising approach for the community to use in its analysis and formulation of a strategy that is more than an empty shell.

Limitations and More Areas for Further Research

As noted, the full extent of health inequities among the LGBTQ+ population is not known (Cahill & Makadon, 2017; Dharma & Bauer, 2017; Wolff, Wells, Ventura-DiPersia, Renson, & Grove, 2017). Although organizations such as Rainbow Health Ontario (2019) have

developed resources and provide training for health professionals, more research is also warranted on how well health professionals are trained to understand LGBTQ+ health issues and how well they implement this knowledge in practice (Abdessamad, Yudin, Tarasoff, Radford, & Ross, 2013; Mulé, McKenzie, & Khan, 2017; Snelgrove, Jasudavisius, Rowe, Head, & Bauer, 2012).

To move beyond the focus on HIV/AIDS, sexually transmitted infections, and “risk” and “risk behaviours” (Hammond, Holmes, & Mercier, 2016; Mulé & Smith, 2014), more research into the structural barriers to health is needed. As noted, however, the SDH framework shows a lack of understanding of the diversity of sexual orientation and gender and identity expression and its structural impact on health. I would argue that the SDH framework may even show an anti-Queer bias as evidenced, for example, by conflating gender and sexual orientation and gender identity and expression.

At the same time, there are important compatibilities between the two approaches. Queer Liberation Theory, like the SDH framework, emphasizes political economy and the importance of social movements for implementing change. Indeed, improving social policy is a frequent goal of an SDH approach.

Recent studies on poverty, homelessness, and economic discrimination among LGBTQ+ are encouraging (Abramovich, 2012, 2016; Ross & Khanna, 2017) and more of this type of work is needed. The work discussed in this research on “minority stress” (Hatzenbuehler, 2009; Meyer, 2003) and an “eco-social approach” (Krieger, 2012) to health are promising developments that should be applied directly to the Queer community.

One of the limitations of this study is that the community groups in the study are not representative of the entire province. Therefore, a broader or more diverse sampling of the

current sector, building on earlier research (Cain, 2002; Cain & Todd 2008), would be useful. Developing research with a larger sample that reflects the range of LGBTQ+ organizations in Ontario is particularly prudent given the divisions within the community identified in this study (i.e., tension among large and small, urban and rural, and racialized and non-racialized organizations). From a Queer Liberation Theory perspective of building solidarity across movements, it would be helpful to know what is creating these divisions and what can be done to ease them. In particular, future research could explore the role of competitive funding models, racism, and individualist ideology in the creation of these divisions.

Moreover, Queer Liberation Theory is willing to push the boundaries of our understanding of political economy well beyond improving social policy. To that end, I will conduct research that will help us better understand the reflections and perspectives of long-time activists, such as those who worked on *The Body Politic*, and on both the historical roots and future directions of the community and the movement. Through this and other research endeavours, I will explore how Queer Liberation Theory can develop a transformative analysis more in line with the vision of the earlier movement that worked to fundamentally change underlying economic structures. Thus, another social division that Queer Liberation Theory must further explore, if it is to be a transformative theory, is that of class divisions. As noted, while the present study focuses more on the political economy of neoliberalism, further development of the theory demands an analysis of sexual orientation and gender and identity expression and class. Does Queer Liberation Theory share a Marxist understanding of the role of the working class in transforming society? Does the experience of the LGBTQ+ community hold important insights for a class analysis? Or is Queer Liberation Theory more inclined toward the incremental changes of social democracy? In any case, we need to grapple with whether the working class

and especially working-class movements are the reservoir of perceived homophobia, and more importantly, what to do about it, if they are. These fundamental issues are urgent, given the “acid rain” effect of the social divisiveness of right-wing populism in Ontario, the United States, and worldwide. The most recent example specific to the LGBTQ+ community, of course, is the repeal of an evidence-based sex education curriculum that addresses the nature of sexual orientation and gender and identity expression and does not shy away from the diversity of Ontario’s classrooms. However, the provincial government is making it clear that all marginalized groups are fair game for funding cuts and social exclusion (Canadian Broadcasting Corporation, 2019; Canadian Federation of Students, 2019; Rizza, 2019).

To reiterate, I am not arguing that an LGBTQ+ Health Strategy will achieve social transformation nor eliminate heteronormativity. However, the process of developing the strategy could be used to also develop the nascent liberationist thinking in the community and the movement, while possibly improving the health inequities faced by the LGBTQ+ community within existing structures. As a future research project, I would like to organize a series of town hall meetings with community organizations to discuss the feasibility and advisability of an LGBTQ+ Health Strategy. Some questions that could be raised in these meetings include the following: Should there be a strategy? What are the advantages and limitations of a strategy? What are the dangers of such a strategy (e.g., assimilation, co-optation)? What would the strategy look like? These meetings would be both a practical exercise in movement-building in the current political climate, and an opportunity to further develop Queer Liberation Theory from the bottom up.

Concluding Thoughts

When I started this academic journey, Ontario had a Liberal government and an openly lesbian premier. Now we have a Conservative government that has blatantly attacked the Queer community by withdrawing an updated, progressive sex education curriculum. With some predicting a provincial economic recession, it appears that any movement-building and theory development will take place in a hostile economic and political environment. One advantage of this hostile political environment, from the point of view of movement-building, is that the Conservatives' ideology removes any illusion of progressiveness that operated under the Liberals.

My research indicates that, among the organizations studied, a structural analysis of Queer health appears to be alive and kicking. However, the staff in this study and their organizations are very much in "survival" mode in the face of increased bureaucratization, competition for funding, and precarious working conditions, as documented in both the literature (Cain, 1997, 2002; Cain & Todd, 2008; Burrowes & Laforest, 2017; Evans & Smith, 2015; Laforest, 2011) and my own research.

The election of the Conservative Ford government makes the future existence of the LHINs precarious (Crawley, 2019). Whether or not the LHINs survive as a policy and programming entity is irrelevant to this research, because it is so clear that government continues to marginalize LGBTQ+ health in their recent online content. It is difficult to know what will happen to the progress on LGBTQ+ health that this research shows has been made in two of the LHINs, particularly in such a hostile environment. The small numbers in the LGBTQ+ population further increase the likelihood for this population to get lost in bureaucratic changes.

With the election of the Ford Conservatives, I thought that the federal government might hold the only plausible route to an LGBTQ+ Health Strategy. However, 2019 is also a federal election year, sure to be full of rhetoric about “saving” money for tax-payers in the face of federal deficits. In this vein, this research has described the impact of this kind of neoliberal ideology, but it’s not clear where neoliberalism is headed (Comaroff, 2011; Cox & Nilsen, 2014). Does the election of the Ford Conservatives represent a revival of neoliberalism that some thought was in decline?

What is clear is that an LGBTQ+ Health Strategy or any improvements that take an SDH approach will certainly require more of that tax-payers’ money. Therefore, the likelihood of improved funding, a broader approach to LGBTQ+ health equity, and the implementation of an SDH framework seems remote in this environment. Thus, given the populist political environment we find ourselves in, Queer Liberation Theory’s liberationist perspective is more necessary than ever to intensify the discussion and the struggle for LGBTQ+ health equity.

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Appendices

Appendix A: Search Strategy

To conduct this review, I used the following key words: social determinants of health; OR health equity AND sexual orientation, sexual minority, LGBTQ+, and sexual orientation and gender identity and expression, to search peer-reviewed journals from Jan. 1, 2009 to Feb. 1, 2019. Inclusion criteria were scholarly North American, English-language articles, excluding book reviews and articles that focused on lifestyle issues (e.g., smoking, substance use, individual behaviours) or had a disease-specific focus other than HIV/AIDS (e.g., cancer patients). Articles also need to focus specifically LGBTQ+ populations or sexual minorities, as opposed to looking “vulnerable” populations generally. I also conducted a manual search to look for references cited in some of the selected articles that met these criteria.

This search yielded 36 studies with a variety of approaches and methods: 10 literature reviews (Connolly, Zervos, Barone, Johnson, & Joseph, 2016; Emlet, 2016; Gaghagan, & Colpitts, 2017; Gkiouleka, Huijts, Beckfield, & Bambra, 2018; Halkitis, Wolitski, & Millett, 2013; Lick, Durso, & Johnson, 2013; Meyer, 2003; Rosenkrantz, Black, Abreu, Aleshire, & Fallin-Bennet, 2016; Valentine & Sherd, 2018; Wade & Harper, 2017); seven commentaries or theoretical papers (Hatzenbuehler, 2009; Krieger, 2012; Lewis, 2017; Logie, 2012; Valdiserri, Holtgrave, Poteat, & Beyrer, 2018; Williams & Mann, 2017; Wolfe, 2018); a policy review (Ylloja & Craig, 2014) and a clinical review addressing the financial hardship associated with HIV/AIDS (Ayala, Bingham, Kim, Wheeler, & Millett, 2012). Ten articles reported on cross-sectional surveys data (Ferlatte, Salway, Trussler, Oliffe, & Gilbert, 2018; Fisher, Irwin, & Coleman, 2014; Hidaka et al., 2014; Ivanković, Šević, & Štulhofer, 2015; Katz-Wise, Reisner, Hughto, & Budge, 2016; Koelmeyer, English, Smith, & Grierson, 2014; Oster et al, 2013;

Rodriguez-Diaz et al., 2016; Steele et al, 2017; Zeeman, Aranda, Sherriff, & Cocking, 2016); two studies reported of sub-analyses of American national databases, (Forsyth & Valdiserri, 2015; Khan, Ilcisin, & Saxton, 2017); and a general survey of mortality in the U.S. (Hatzenbuehler, Bellatorre, Lee, Finch, Muennig, & Fiscella, 2014) and one record review (Blosnich et al., 2017). Three qualitative studies reported the findings from focus groups and/or interviews (Hill et al., 2018; Ross, Dobinson, & Eady, 2010; Smith & Turell, 2017).

Appendix B: TPCS Certificate



**PANEL ON
RESEARCH ETHICS**
Navigating the ethics of human research

TCPS 2: CORE

Certificate of Completion

This document certifies that

Cameron McKenzie

*has completed the Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans
Course on Research Ethics (TCPS 2: CORE)*

Date of Issue: **7 November, 2016**

Appendix C: Ethics Approval



OFFICE OF
RESEARCH
ETHICS (ORE)
5- Floor, Kaneff
Tower



Certificate #:	STU 2017 - 019
Approval Period:	02/06/17-02/06/18

ETHICS APPROVAL

To: **Cameron McKenzie**
Graduate Student of Health Policy & Management, Faculty of Health
[REDACTED]

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics
(on behalf of Denise Henriques, Chair, Human Participants Review Committee)

Date: Monday, February 06, 2017

Title: **Community Perceptions and Experiences with Funding LGBTQ Health Initiatives in the Greater Toronto Hamilton Area**

Risk Level: Minimal Risk More than Minimal Risk

Level of Review: Delegated Review Full Committee Review

I am writing to inform you that this research project, "**Community Perceptions and Experiences with Funding LGBTQ Health Initiatives in the Greater Toronto Hamilton Area**" has received ethics review and approval by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

Note that approval is granted for one year. Ongoing research – research that extends beyond one year – must be renewed prior to the expiry date.

Any changes to the approved protocol must be reviewed and approved through the amendment process by submission of an amendment application to the HPRC prior to its implementation.

Any adverse or unanticipated events in the research should be reported to the Office of Research ethics [REDACTED] as soon as possible.

For further information on researcher responsibilities as it pertains to this approved research ethics protocol, please refer to the attached document, "**RESEARCH ETHICS: PROCEDURES to ENSURE ONGOING COMPLIANCE**".

Should you have any questions, please feel free to contact me at: [REDACTED] or via email at: [REDACTED]

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LL.M.
Sr. Manager and Policy Advisor,
Office of Research Ethics

RESEARCH ETHICS: PROCEDURES to ENSURE ONGOING COMPLIANCE

Upon receipt of an ethics approval certificate, researchers are reminded that they are required to ensure that the following measures are undertaken so as to ensure on-going compliance with Senate and TCPS ethics guidelines:

1. **RENEWALS:** Research Ethics Approval certificates are subject to annual renewal. **It is the responsibility of researchers to ensure the timely submission of renewals.**
 - a. As a courtesy, researchers will be reminded by ORE, in advance of certificate expiry, that the certificate must be renewed. Please note, however, it is the expectation that researchers will submit a renewal application prior to the expiration of ethics certificate(s).
 - b. **Failure to renew an ethics approval certificate** (or to notify ORE that no further research involving human participants will be undertaken) **may result in suspension of research cost fund and access to research funds may be suspended/ withheld.**
2. **AMENDMENTS:** Amendments must be reviewed and approved **PRIOR** to undertaking/making the proposed amendments to an approved ethics protocol;
3. **END OF PROJECT:** ORE must be notified when a project is complete;
4. **ADVERSE EVENTS:** Adverse events must be reported to ORE as soon as possible;
5. **POST APPROVAL MONITORING:**
 - a. More than minimal risk research may be subject to post approval monitoring as per TCPS guidelines;
 - b. A spot sample of minimal risk research may similarly be subject to Post Approval Monitoring as per TCPS guidelines.

FORMS: As per the above, the following forms relating to on-going research ethics compliance are available on the Research website:

- a. Renewal
- b. Amendment
- c. End of Project
- d. Adverse Event

Appendix D: Informed Consent Letter

Informed Consent Letter

Date _____

Study name: Community Perceptions and Experiences with Funding LGBTQ+ Health Initiatives in the Greater Toronto and Hamilton Area

Researchers: Cameron McKenzie, PhD Candidate

School of Health Policy and Management, Faculty of Health,

Contact: _____

Purpose of the research:

My research aims to examine how community organizations in the Greater Toronto and Hamilton Area (GTHA) focusing on Lesbian, Gay, Bi, Trans, Queer/Questioning (LGBTQ+) health perceive and experience the dynamics of policy making, past, and present. I want to understand how these organizations both shape and respond to health funding policy both historically and in the current political context. The findings will be presented in a dissertation, peer-reviewed journal articles, and at both academic and community conferences.

What you will be asked to do in the research:

I will be asking you to participate in a 30–45 minute, semi-structured interview probing your experience and perspectives on the dynamics of policy making, past and present (as applicable). The interview will explore your experience and perspectives based on your particular role in program and/or service delivery, including past and present advocacy and activism in the LGBTQ+ community (where applicable). This interview can be conducted in person, by telephone or by email at your convenience. Interviews conducted in person or over the telephone will be digital-recorded for transcription and data analysis, with your consent.

Risks and discomforts:

There are no anticipated or known risks to the participants except for possible discomfort talking on this subject. Participants will be able to withdraw from the study at any time and will have the option of anonymity.

Benefits of the research and benefits to you:

You will have an opportunity to voice your opinions and help to illuminate possible strategies for navigating the current funding climate for LGBTQ+ community-based health services and programs. You may also feel good in the knowledge that you have contributed to the ongoing development of history of the queer and trans community.

Voluntary participation:

You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researcher (Cameron McKenzie) or with researchers and staff at York University, either now or in the future.

Withdrawal from the study:

You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researcher (Cameron McKenzie), York University, or any other group associated with this project. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality:

Your confidentiality is paramount and no identifying information will be disclosed without your consent, unless you choose otherwise. All data (consent forms, digital recordings, and transcripts) will be kept in a locked file cabinet at all times and on a password-protected computer. Only I have access to the data. All information you supply during the research will be held in confidence and unless you specifically indicate your consent, your name will not appear in any report or publication of the research. Confidentiality will be provided to the fullest extent possible by law. The data will be stored until two years from the date of ethics approval. I will destroy any data on my computer, USB keys, and hard copies after two years.

In the event your identity is useful to the findings of the research and you consent to disclosing your identity, please sign below:

I consent to my name and title being associated with this study _____

Questions about the research?

If you have questions about the research in general or about your role in the study, please feel free to contact my supervisor Dr. Nick Mulé either by telephone at [REDACTED] or by e-mail ([REDACTED]). This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If

you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University (telephone [REDACTED] or e-mail [REDACTED])

Legal Rights and Signatures:

I _____, consent to participate in 'Community Perceptions and Experiences with Funding LGBTQ+ Health Initiatives in the Greater Toronto and Hamilton Area' conducted by Cameron McKenzie. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature _____

Date _____

Participant

Signature _____

Date _____

Principal Investigator

Appendix E: Interview Questions for Bureaucrats

1. Tell me about yourself and your background. What is your role in [name of policy and/or funding body]?
2. Is the funding program that you administer mandated by a specific policy? In other words, does the government have high-level goals and objectives on LGBTQ+ health? Or HIV/AIDS specifically? Is there a policy document that I could look at?
3. What are the main goals of your funding policies? For example, would you say the focus of the programs you fund is prevention, community development, treatment, all of these? Do any of the funding policies address the social determinants of health, such as poverty?
4. How does the government ensure accountability both to the taxpayer and the LGBTQ+ community for its funding dollars?
5. In what ways is evidence-based programming related to your funding decisions? In what ways does advocacy based-programming relate to your funding decisions?
6. In what ways are groups allowed to interact with the [name of funding body]? In what ways do you connect with stakeholders?
7. Do you think that the work that you do as a funder and the work that the organizations you fund do, contribute to changing perceptions of “queerness”? If so, how?
8. Are there emerging policies, for example, an LGBTQ+ Health Strategy? If so, how are you consulting the community? If not, why do you think there is no strategy? Do you think there should be an LGBTQ+ Health Strategy? Why or why not? What would its purpose be?
9. Apart from an actual LGBTQ Health Strategy, what current health policies exist that are of relevance to LGBTQ+ people?
10. Are there any other issues that you think are important for me to understand?

11. Do you have any questions for me?

Appendix F: Interview Questions for Community Organizations

1. Tell me about yourself and your background. What is your role in the organization? How long have you been working with this organization? [Probe for longstanding involvement: Describe how the organization and its work have changed over time. May want to probe about nature and extent of volunteer work.]
2. Tell me about the programs and services your organization offers. [Probe: Try to get at number of staff, number of full-time staff, number of part-time, number and duration of contracts, and how they feel this affects the work.]
3. Describe the advocacy and social justice work that you do in [name of organization] for the queer and trans community. [Probe: Do you ever use the term “social determinants of health” in your work? What does that term mean to you in your work?]
4. What is the role of volunteers in your organization? [Does staff feel volunteers are essential to the organization? Do volunteers do any of the front-line work (get details)? Do they do any of the advocacy/social justice work?]
5. Have you worked or volunteered elsewhere in the LGBTQ+ health sector? If so, for how long?
6. Can you give me examples of how your organization works with other organizations on causes of common concern? If so, how would you describe the goals and politics of this collaboration? If not, why not? [Probe for whether they think about this as a work collaboration, or a movement, or political coalition.]

7. Do you feel like your work in [name of organization] is making a difference in the queer community? Could you talk about this a little, give some examples? [How does your work contribute to social perceptions of “queerness”?]
8. Which specific funding programs and procedures govern your organization’s mandate and funding?
9. Do you feel that the current funding policies are effective? In what ways are current funding policies supportive or not?
10. Do your funders require evaluation of the effectiveness of your programs? If no, why do you think that is? If yes, are you given criteria for how to do so? [Are they required to have professionals, evidence-based (informed) criteria, is there an emphasis on numbers of people seen?]
11. Are there certain types of work that the organization would like to do but cannot do? [Probe for advocacy/ community development; do volunteers kind of do stuff on the side that helps the work of the organization?] What prevents the organization from doing this work? In what ways do you interact with the funder(s)? How do the funder(s)’ rules and regulations impact on your job?
12. In what ways does your organization participate in government consultation? Examples? How meaningful is the consultation process? Can you identify changes that result from consultation?
13. Are you aware of any emerging government policies or changes to policies? Do you have a role in developing these policies? If yes, please describe your role and your concerns. If not, why do you think you are not involved and what are your concerns about that?

14. If you were a policy maker, and given your experiences in the community, what would change about the funding rules? Maybe the focus should not be to focus so much on funding, but policy development or both?
15. Do you think there should be a federal and/or province-wide LGBTQ+ health policy? If so, why? If not, why not? If yes, what would you like to see in that policy? Would you like to see your organization expand its health mandate beyond HIV? How about other LGBTQ+ organizations?
16. Is there anything else you think I should know regarding funding policies or anything else about your organization?
17. Do you have any questions for me?

Appendix G: Statement of Authors' Contributions

LGBTQ+ and Ontario's Health Care Policies and Programs: Author's Roles

Nick Mule and Maryam Khan authorize Cameron McKenzie to use our co-authored manuscript "LGBTQ+ and Ontario's Health Care Policies and Programs" for his manuscript-based dissertation. In their supportive roles, Nick Mule, conducted and wrote the content analysis of the MOHLTC websites for both periods of the study. Maryam Khan provided support in the content analysis of the LHINs website, providing the findings for 7 of the 14 websites studied for both periods of the study.

As lead author, Cameron McKenzie was responsible for the following components of the manuscript:

- literature review
- study design for the LHINs section
- coding scheme for the content analysis of the LHINs
- findings for 7 of the 14 LHINs
- compilation and editing of findings on the LHINs
- conduct and analysis of the interviews (obtained research ethics approval)
- conclusion
- editing of the compiled manuscript
- Submitting the manuscript to the *Journal of Homosexuality*

Lead Author: Cameron McKenzie Signature:

Co-author: Nick Mule Signature:

Co-author: Maryam Khan Signature:

