

Life with HIV in a Suburban Community: An Exploration of Experiences Pertaining to
Health and Social Care Service Access

by

Derek Manis

A Thesis Submitted in Partial Fulfillment
of the Requirements for the Degree of

Master of Health Sciences

in

The Faculty of Health Sciences
Program

University of Ontario Institute of Technology

March, 2017

© Derek Manis, 2017

Acknowledgement

First, I must recognize and acknowledge my thesis supervisor, Dr. Brenda Gamble, for her unwavering encouragement, support, and mentorship throughout my undergraduate and graduate education at UOIT. I could not have imagined, or have asked for, a better experience and I am incredibly privileged to work with and learn from you. I also need to extend my sincerest gratitude to Dr. Caroline Barakat-Haddad and Dr. Vicki Smye for serving on my thesis committee and offering support whenever I needed it. I also need to mention Dr. Gail Lindsay, who, although not a member of my thesis committee, has supported me and my growth in performing qualitative research.

Second, I would like to thank the AIDS Committee of Durham Region (ACDR) for their support of my research, assisting with the recruitment of co-participants, and providing me with a space to conduct interviews. In particular, I would like to thank Margaret McCormack for connecting me with the dedicated staff at the ACDR. Additionally, I must recognize the contribution that all co-participants in this research made, sharing their experiences accessing health and social care services within their suburban communities.

Third, I would like to acknowledge and thank my friends who have supported and encouraged me on this journey. I would like to give a special mention to Lydia, Krystal, Meghan, and Ivayla. Thank you for all that you have done over the past decade and continue to do to make me feel valued and an important part of your lives.

Finally, to my mom and family, thank you for always supporting my dreams and aspirations. Your support knows no limits!

Abstract

Literature examines HIV within urban or rural contexts; the suburban gradient is not sufficiently described, despite how an overwhelming proportion of Canadians live in this form of community. This inquiry investigated how people living with HIV (PLWH) in a suburban, Ontario, Canada community access health and social care services. Using hermeneutic phenomenology associated with Martin Heidegger, in-depth interviews with PLWH were conducted to understand their experience of accessing care. Thirteen co-participants were interviewed and six metathemes were identified in their experiences: fear of disclosure and stigmatization; personal and unintentional biases about HIV; isolation; transportation, cost, and time: barriers to access; flawed delivery of health care services; and inefficient, antiquated social care service delivery. These findings have implications for community-based, interprofessional health and social care services; how health and social care services are delivered; health care professional training and sensitivity to the diverse needs of PLWH; and ageing with HIV.

Keywords: Community-based care, suburban community, transportation, interprofessional care, HIV

Table of Contents

Acknowledgement	ii
Abstract	iii
Chapter 1: Introduction	1
1.1 Inquiry Context and Setting	2
1.2 Overview of Thesis	2
Chapter 2: Literature Review	4
2.1 Search Strategy, Inclusion and Exclusion Criteria	4
2.2 Defining Suburban Communities and Their Influence on Health and Wellness	6
2.3 Transportation Within Suburban Communities and its Effects on Accessing Health Care	9
2.4 HIV Stigma in Low Prevalence Communities and Health Care Settings	13
2.5 Problematic Substance Use in Suburban Communities	16
2.6 Access to Primary Care and Patient Engagement in HIV Care	18
2.7 Conceptual Framework	22
2.8 Moving Forward: Creating Healthier Communities and Health Care Systems	23
Chapter 3: Methods, Data Collection and Analysis	25
3.1 Ethical Considerations	25
3.1.1 Research Ethics Board Approval	25
3.1.2 Protecting Co-Participant Confidentiality	25
3.1.3 Obtaining Consent	26
3.2 Research Design	27
3.2.1 Rationale for Social Constructivist Paradigm and Qualitative Methodology ..	27

3.2.2 Phenomenology	28
3.3 Setting and Co-Participants	29
3.3.1 AIDS Committee of Durham Region (ACDR)	29
3.3.2 Inclusion and Exclusion Criteria	30
3.3.3 Recruitment Strategy	30
3.3.4 Sampling Procedures	32
3.4 Data Collection.....	33
3.4.1 In-Depth Interviews.....	33
3.4.2 Data Storage and Management.....	34
3.4.3 Researcher Experience	35
3.5 Data Analysis	36
3.5.1 Data Analysis Procedures.....	36
3.5.2 Evaluating Authenticity and Trustworthiness	38
3.6 Study Strengths and Limitations	39
Chapter 4: Results	41
4.1 Co-Participant Demographics	41
4.2 Fear of Disclosure and Stigmatization	42
4.2.1 Fear of Disclosure.....	43
4.2.2 Lived Stigmatization.....	45
4.2.3 Intersecting Stigmas	46
4.2.4 Pharmacies.....	47
4.2.5 Stigmatization by Health Care Practitioners and Within Health Care Settings	50
4.3 Personal and Unintentional Biases About HIV	52

4.3.1 Personal and Unintentional Biases About HIV Among Health Care Practitioners	52
4.3.2 Personal and Unintentional Biases About HIV Among People Within the Community	53
4.4 Isolation	54
4.4.1 Isolating Self.....	54
4.4.2 Isolation Attributed to a Lack of Community	55
4.5 Transportation, Cost, and Time: Barriers to Access	56
4.6 Flawed Delivery of Health Care Services	59
4.6.1 Deficiencies and Deflected Needs in Primary Care Settings	59
4.6.2 Sharing Health Information Versus Collaborating on Care Plans.....	60
4.6.3 Care Delivery in Silos.....	61
4.6.4 Ageing with HIV: The Need for Community-Based Interprofessional Care ...	61
4.7 Inefficient, Antiquated Social Care Service Delivery	63
4.7.1 Poorly Coordinated and Restrictive Social Care Services.....	63
4.7.2 Disconnect Between Social Care and Health Care Service Delivery.....	65
Chapter 5: Discussion and Conclusions.....	66
5.1 Stigmatizing Experiences and Education About HIV	66
5.1.1 HIV Stigmatization and Gender	66
5.1.2 HIV Stigmatization Within Communities	67
5.1.3 HIV Stigmatization Within Health Care Settings.....	68
5.1.4 Education About the Needs of PLWH	69

5.1.5 Outreach Via Social Media to Increase Education About HIV and Mitigate Stigma.....	69
5.2 Transportation, Access to Services, and Community Development.....	70
5.2.1 Transportation Barriers.....	71
5.2.2 The Role of Community-Based Organizations and Community Development.....	73
5.3 Cohesive Health and Social Care Service Delivery	75
5.3.1 Reducing Unmet and Deflected Health Needs in Primary Care	75
5.3.2 Integration of Pharmacies and Pharmacists in Primary Care	76
5.3.3 Interprofessional, Collaborative Care and Ageing Within Communities.....	78
5.3.4 Amalgamating Health and Social Care Delivery	80
5.4 Conclusions and Opportunities for Further Inquiry	81
Appendix A: UOIT REB Approval	83
Appendix B: Letter of Invitation and Consent Package	85
Appendix C: AIDS Committee of Durham Region Letter of Approval.....	88
Appendix D: Verbal Recruitment Script for ACDR Staff.....	89
Appendix E: Verbal Recruitment Script for Personal Networks.....	89
Appendix F: Interview Guide	90
Appendix G: Audit Trail of Themes Identified from In-Depth Interviews	93
References.....	127

Chapter 1: Introduction

An overwhelming proportion of Canadians live in suburban communities (Gordon & Janzen, 2013; Gordon & Shirokoff, 2014; Moos & Mendez, 2014). Yet there is a paucity of public and community health research conducted in Canada pertaining to how the components and structures found within them, such as sprawl and limited public transportation services, all impact access to health and social care services, and, consequently, health and wellness. Moreover, because suburban communities are unique and distinct from urban or rural ones (Forsyth, 2012; Hancock, 2000), it is essential to undertake research that establishes how to address and mitigate possible health inequities stemming from their design.

HIV is a chronic health condition because people living with HIV (PLWH) are living longer than ever before due to regular and on-going advances in antiretroviral therapy (Brooks, Buchacz, Gebo, & Mermin, 2012; Kendall et al., 2015). Many determinants of an HIV diagnosis, which include but are not limited to: injection drug use and unprotected sex, fit within the context of inner city health issues. But considering how the suburbs are home to many Canadians coast-to-coast, it would follow that these behaviours and PLWH are also present in suburban communities. There are varied professionals and organizations – health researchers and practitioners, policymakers, and community-based health and social care organizations – that would benefit from the answers to the following research questions: (1) How do suburban PLWH access health and social care services; and (2) How does the structure, design, and population demographics of the suburban community influence and affect the access of PLWH to health and social care services? Additionally, consideration of how social norms within

suburban communities where PLWH reside also contribute to access would be beneficial (e.g., norms that are in any way prohibitive and/or discriminatory could significantly reduce access to care and increase morbidity and mortality for PLWH) (Earnshaw, Smith, Chaudoir, Rivet Amico, & Copenhaver, 2013; Mill et al., 2009).

1.1 Inquiry Context and Setting

Durham region is located east of Toronto, and has a population of 594,000 (Region of Durham, 2016). Durham region is primarily suburban, but there are areas in the north part of the region that are rural (Gordon & Shirokoff, 2014). Durham region is a unique setting to conduct this inquiry, as, to my knowledge, there are no studies on PLWH in this region that could be found in major databases (e.g., CINAHL, PubMed, Web of Science, Scopus, etc.).

1.2 Overview of Thesis

In Chapter 2, I present a review of the literature, including how suburban communities were defined in this inquiry and how transportation within suburban communities affects access to health and social care services. Moreover, in this chapter I discuss HIV stigma in low prevalence environments and within health care settings. Further literature related to problematic substance use within suburban communities, access to care, and patient engagement within HIV care is also reviewed to inform the inquiry's research questions.

Then, in Chapter 3, I present the ethical considerations, setting, and eligibility criteria for co-participants to engage in the inquiry. In this chapter, I also present the study design and how the data were collected (e.g., in-depth interviews) and managed. In

addition, data analysis procedures and strengths and limitations of the study are presented.

Then, in Chapter 4, I present the results from the in-depth interviews with PLWH. Finally, in Chapter 5, I discuss the results, summarize the inquiry, and offer suggestions for future research in the area.

Chapter 2: Literature Review

This inquiry seeks to answer the following research questions: (1) How do suburban PLWH access health and social care services; and (2) How does the structure, design, and population demographics of the suburban community influence and affect the access of PLWH to health and social care services? This chapter contains the search strategy for gathering literature, defines suburban communities and the role that transportation within suburban communities plays in regards to health care service access. The chapter goes on to explicate HIV stigma in low prevalence communities, such as suburban communities, and in health care settings. Further review of literature pertaining to problematic substance use within suburban communities – one possible cause of an HIV diagnosis – is also included herein. Finally, literature pertaining to access to care and patient engagement within HIV care is also reviewed.

2.1 Search Strategy, Inclusion and Exclusion Criteria

PubMed, CINAHL, Scopus, and Google Scholar were the databases used to search and gather literature because they are large, comprehensive indexes of peer-reviewed health and social science citations. Google web searches were also used to broadly acquire sources related to Canadian suburban communities. The primary keywords used included: *suburban population*, *residence characteristics*, *transportation*, *urban sprawl*, *socioeconomic factors*, *HIV*, *stigma*, *qualitative research*, *health services accessibility*, *delivery of health care*, *primary health care*, and *health services needs and demands*. Some keywords were altered to locate literature when a database search did not yield results. For example, *suburban population* was modified to *suburban health*, *Canadian suburbs*, *community*, and *suburban*. These keywords were selected because

they capture the specificity of the location, describe characteristics of the population, and examine defining features of the health care services expressed in the aim of the inquiry. The method used for gathering literature in this chapter is consistent with the description of a second-generation literature review (see Popay & Mallinson, 2010; Pope, Mays, & Popay, 2007). The initial search results yielded a total of 1449 articles that were exported into EndNote, of which 594 duplicate articles were removed. After screening the titles of those 855 articles for relevance to the research questions, 645 articles were excluded and 210 articles were brought forth to the next stage of the review. Of those articles, 125 were excluded after screening the article's abstract and 85 were selected for full text review. After full text review, 59 articles were deemed irrelevant to the research questions and the remaining 26 articles were utilized for the literature review. Each source's reference list was also reviewed; additional, pertinent sources were retrieved and included in the literature review.

In order to be included in the review, I ensured each source would have aimed to accomplish at least one of the following: (1) Explain or provide further information on suburban community design or Canadian suburban communities in relation to accessing health and social care services; (2) Report on perceptions and experiences of living in a suburban community in Canada, the United States, or Australia in relation to accessing health and social care services; (3) Discuss the role that transportation plays in accessing health and social care services; (4) Explore HIV stigma broadly, or in low prevalence or health care settings; (5) Investigate problematic or chronic dependent substance use in suburban communities; and (6) Examine health care access, health service utilization for PLWH, or patient engagement within HIV care.

Studies that examined suburban communities in Europe, Asia, Africa, and South America were excluded because their community structure or design would be different than what would be found within a Canadian suburban community (see Hancock, 2000 on North American suburbs), thereby severely restricting transferability. In addition, many countries in South America, Africa, and Asia are lower income countries (Organisation for Economic Co-operation and Development [OECD], 2015), and they would have different social determinants and variables that impact health, many of which would not be applicable or present within Canada. Additional exclusion criteria included those published in other than the English language, and only studies published after 1996, which was when antiretroviral medications were introduced and significantly ameliorated health outcomes for PLWH (Montaner et al., 2014). Studies that only examined the incidence and prevalence of obesity, physical activity or inactivity, or mental health without any discussion of living with HIV in a suburban environment were also excluded because of their irrelevance to the experience of accessing health and social care services for PLWH. Finally, because this inquiry focuses on adults, studies conducted on children in suburban neighbourhoods were also excluded.

2.2 Defining Suburban Communities and Their Influence on Health and Wellness

Forsyth (2012) articulated the importance of suburban communities in her review of the literature because they are, and will continue to be, an extremely prevalent form of community in which people reside globally. Given this importance, Forsyth explained that suburbs are, and have been, challenging to define because they are contingent upon how they are measured, and thus a universal definition of a suburban community simply does not exist. However, Forsyth provided common characteristics and features of

suburban communities that can be easily identified in North America: detached homes, strip malls, massive shopping centres, and low population density. Turcotte (2008a) also acknowledged some of those characteristics as ones found in many Canadian suburban communities, but, more importantly, Turcotte identified that there are many different approaches to defining Canadian suburbs, thereby echoing Forsyth's position.

Turcotte (2008a) presented four different ways by which suburban communities could be measured and defined: political or administrative boundaries, business boundaries, distance from the city centre, and neighbourhood density. Turcotte elected to focus on defining suburbs by the distance from the city centre in his article because this is where many employment opportunities typically exist, and this particular method is very effective for measuring commuting and travel distances. Although each approach presented by Turcotte to define a Canadian suburban community is valid and has its own benefits and drawbacks, the findings yielded by each approach varies significantly because each approach allocates a different weight on different variables (e.g., distance from a particular location in the city centre versus classification of neighbourhoods or areas, etc.). The fact that suburban communities are prevalent domestically and internationally and lack standardized definitions and universal measurement tools supports the need for further research.

Gordon and Janzen (2013) performed extensive calculations and research to test various hypotheses to establish a working definition of a suburb that would have practical applications for Canadian policymakers. They determined examining modes of transportation, which is a variable collected in the long-form census, to be valuable in distinguishing between types of neighbourhoods. After excluding areas that were clearly

city centres or rural, they defined the remaining areas as suburbs. This finding indicated that over 75 per cent Canadians living in metropolitan areas were in suburbs – not city centres; however, the criteria used by Moos and Mendez (2014) to categorize neighbourhoods on a gradient of urban to suburban took into account the population of the metropolitan area and estimated that an average of 44 per cent of Canadians live in suburban communities. Regardless of the methodology and criteria used to measure or classify suburban communities across Canada, further research should be performed to ascertain how health and social care services are accessed within suburban communities because of their prevalence. Furthermore, marginalized populations, such as PLWH, may likely require on-going access to health and social care practitioners to manage their health. If they encounter barriers in access that are rooted in the suburban community's design (e.g., sprawl and long distances between residential and commercial, health or social service locations), it then becomes critical for urban planners, policymakers, and health system executives to collaboratively assess how the community's design should better facilitate the promotion of health and wellness and maximize equity.

Gordon and Shirokoff (2014) revealed that Canada's greatest population growth occurred in suburban neighbourhoods that they classified as automobile-dependent, or where cars are used as the primary or sole mode of transportation by residents. Examples of such communities include many within the Durham, York, and Peel regions, which all surround Toronto – Canada's largest urban centre. For this inquiry, I will utilize the automobile-dependent suburban community definition.

Gordon and Shirokoff (2014) concluded that the substantial growth in suburban settings is especially important for public health policies and the design of healthy

communities because they expressed concern over the emissions produced from the numerous vehicles and this effect on air quality. Other authors (Frumppkin, 2002; Hancock, 2000) who critiqued suburban environments, sprawl, and their effects on the health of its residents, also noted the concern of air quality. There is already evidence in the literature that suburban communities are bad for the environment, contribute to poorer health states, and erect barriers in accessing services (e.g., Andrews, 2010; Frumpkin, 2002; Hancock, 2000, 2011), but there is an absent body of research specifically examining Canadian suburban community design and its influence on health and health and social care service access. In light of the prevalence of suburban communities in Canada and this gap in research, understanding these effects would contribute to improving the health and wellness of many Canadians, including PLWH.

Wilson et al. (2004) provided evidence of how negative perceptions and opinions of the physical attributes within a person's suburban neighbourhood or community were correlated with more chronic health conditions, whereas positive perceptions and opinions contributed to better physical and emotional well-being. These findings suggest that community structure and design are important enablers or detractors of health and wellness. In addition, because sprawl is a unique characteristic of suburban communities (Forsyth, 2012; Frumpkin, 2002; Hancock, 2000), it is important to understand how it affects health and how health and social care services are accessed.

2.3 Transportation Within Suburban Communities and its Effects on Accessing Health Care

It is common for many suburban communities to be designed in a manner that favours transportation by car or personal automobile, rather than by an extensive public

transit system (Forsyth, 2012; Turcotte, 2008b). Syed, Gerber, and Sharp (2013), Silver, Blustein, and Weitzman (2012), and Andrews (2010) all made reference to how lower socioeconomic status and not having a car are related to decreased access to health care services. Paez, Mercado, Farber, Morency, and Roorda (2010) investigated areas of low accessibility to health care facilities in the Montreal Island area for older adults. Older adults may face similar barriers in accessing health and social care services as PLWH. For instance, they may not have a car or driver's license and rely on public transportation to attend medical appointments. Paez et al. noted how the person's ability to travel to health and social care services is a more important variable to measure access to health care services than the relationship between the distance and time spent travelling to care. Other studies found that the distance-time traveling to care relationship were mixed, inconclusive, and thus called for further research (see Syed, Gerber, & Sharp, 2013). As none of the studies examined by Syed et al. in their systematic search of the literature took place within Canada, it is essential to establish the extent to which the relationship between distance and time spent travelling to care affects Canadian PLWH in suburban communities.

The possession of a car could be considered a characteristic of higher socioeconomic status; and when socioeconomic status, health, and health care access or service utilization are examined, many social determinants of health (see Raphael, 2010) have a strong influence over how they each relate to each other. Moreover, other authors (Eberhart et al., 2014, 2015; Kaukinen & Fulcher, 2006) acknowledged that transportation is a crucial component of access to care. Geography or location of the health service is a factor considered by patients when making a decision to seek care

(Aday & Andersen, 1974; Eberhart et al., 2015; Paez, Mercado, Farber, Morency, & Roorda, 2010), and thus the interconnectivity between distance, travel modes and time, and specific health services should not be underestimated as a critical determinant of health and well-being.

Social exclusion – an important social determinant of health – encompasses a person's inability to access health and social care services (Mikkonen & Raphael, 2010). Without access to affordable transportation or the ability to be mobile, people become isolated and, consequently, excluded from their communities (Mackett & Thoreau, 2015). As sprawl present within suburban environments could isolate people who rely on public transportation systems, it is conceivable that social exclusion would intersect with other social determinants – housing, unemployment and job security, among others – that create inequity and compound barriers for PLWH. Social exclusion is known to contribute to poorer health states, such as depression, because a person is deprived of many benefits gleaned from participating in society and with others (Mackett & Thoreau, 2015). Social inclusion is then very important for creating, developing, and sustaining cohesive and supportive communities and environments (Boniface, Scantelbury, Watkins, & Mindell, 2015). Therefore, ensuring accessible and affordable transportation is key to addressing and mitigating social exclusion within communities. Additionally, its provision is important to enable the development and sustainability of supportive communities with shared experiences (e.g., PLWH).

In the context of HIV care, transportation is frequently cited as a significant barrier for PLWH (Cunningham et al., 1999; Heckman et al., 1998; Kempf et al., 2010; Sarnquist et al., 2011), which shows that it plays a substantial role in accessing health

services to maintain good health. In Australia (Carman, Grierson, Pitts, Hurley, & Power, 2010) and in the United States (Eberhart et al., 2014, 2015), similar phenomena regarding PLWH and transportation occurred: A significant proportion of PLWH commute, and sometimes large distances, to access HIV-related care and services because these services are not accessible within their nonurban communities. Eberhart et al. (2015) also suggested reasons why this happens: PLWH may try to mitigate stigma originating from a smaller community (see Reif, Whetten, Ostermann, & Raper, 2006 for similar findings in their study); and they may seek care near their place of employment or area that they frequent quite often. All of these findings support how transportation, community design, and stigma intersect to influence access to health and social care services within suburban communities for PLWH, which further illustrates that their relationship should be examined more closely.

In Toronto, Kaukinen and Fulcher (2006) established that HIV services, which can include HIV testing and treatment, needle exchange and harm reduction services, and social programs, among others, are unequally distributed across the city with the northern (i.e., North York), western (i.e., Etobicoke and York), and, especially, eastern (i.e., Scarborough and East York) areas at a disadvantage compared to the urban core or Toronto proper. In other words, if a person does not live or reside in the city centre where many of these services are located, then the distance and time needed for travel to access them would be a barrier and have a prohibitive influence on the decision to seek or access the service. Thus, considering there is no research that examines HIV in a Canadian suburban community, soliciting from PLWH how transportation and public transportation systems affect their access to health and social care services would be of significant

benefit. Their experiences and insights would be important data to determine optimal locations where health services and HIV-specific health services should be located to improve access and reduce inequities arising from a person's place of residence and community infrastructure determinants.

2.4 HIV Stigma in Low Prevalence Communities and Health Care Settings

Stigmatization of HIV infection has existed since its discovery and combatting it remains an important component of public health efforts to reduce its incidence (Berg & Ross, 2014; Chambers et al., 2015; Klein, Karchner, & O'Connell, 2002; Relf & Rollins, 2015). Stigma, according to Link and Phelan (2001), is "when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold" (p. 367). In light of this definition, PLWH in low prevalence communities, which include suburban and rural communities, can be especially stigmatized because of conservative and right-wing political ideologies, decreased anonymity, and limited HIV-specific services, such as medical specialists and social programs (Gonzalez, Miller, Solomon, Bunn, & Cassidy, 2009; Zukoski & Thorburn, 2009).

In addition, PLWH in low prevalence contexts may not disclose their seropositivity to health care practitioners or others in their community because of fears of social rejection and isolation (Loutfy et al., 2012; Zukoski & Thorburn, 2009). Social rejection and isolation are two components of perceived stigmatization (Fife & Wright, 2000). These fears and their associated outcomes can negatively impact any individual and contribute to depression and other mental health issues, such as problematic substance use leading to addiction in coping with stigma (Chambers et al., 2015; Cramer,

Colbourn, Gemberling, Graham, & Stroud, 2015; Green & Feinstein, 2012). While many of these findings were attributed to American and international contexts, it is important to understand and confirm whether these experiences are transferable to Canadian suburban communities.

HIV stigma intersects with many other health and social conditions, including but not limited to: injection drug use, sex work, ethnicity, gender, and sexual identity and orientation (Earnshaw, Smith, Cunningham, & Copenhaver, 2015; Logie, James, Tharao, & Loufty, 2011; Loutfy et al., 2012). Earnshaw, Smith, Chaudoir, Rivet Amico, and Copenhaver (2013) found that the prejudices and stereotypes possessed by others and projected onto PLWH were more likely to result in comorbidities of other chronic health conditions and increased progression of HIV (i.e., low CD4 cell counts). This mechanism would be considered internalized stigma, which is defined as when the person being stigmatized owns the stereotypes and expects social isolation and rejection to occur (Livingston & Boyd, 2010; Ritsher & Phelan, 2004). Logie, James, Tharao, and Loufty (2011) illustrated the oppression that many PLWH experience in society and within their communities and networks pertaining to a person's HIV diagnosis or presumed manner of HIV acquisition. These findings demonstrate how the intersecting stigmas can produce negative, synergistic effects on PLWH that influence how they manage their health and well-being or, unfortunately, neglect it. In addition, the negative effects of intersecting stigmas highlight the fact that PLWH experience profound inequity within many levels of society that require remediation. Therefore, examining the experiences of PLWH in a suburban community and understanding how stigma affects their health and health care

seeking behaviours are essential to promoting health, reducing inequities, and creating safe and inclusive communities.

Despite the advances in medical knowledge about HIV, many PLWH still experience stigma from health care practitioners. In Canada, Gagnon (2015) and Mill et al. (2009) provided many accounts from PLWH of inappropriate and unethical behaviours from health care practitioners. However, these events occurred, generally, when PLWH needed to seek urgent or emergent care outside of their HIV-focused care hub. For PLWH who live in suburban communities where HIV-focused care hubs may not exist, or exist to a much lesser extent than in their urban counterparts, it is reasonable to predict, based on the findings from Gagnon and Mill et al., that episodic stigmatization from health care practitioners occurs.

In light of that finding, it is important to investigate whether or not, how often, and what distances PLWH travel to access HIV-related care to mitigate any degree of stigmatizing experiences in their community, and how the traveling to care affects how they manage their health. Berg and Ross (2014) found in their interviews and focus groups with HIV negative gay and bisexual men in southern USA that HIV stigma forced them to seek HIV health services, such as testing, outside of their communities to preserve their anonymity. Gagnon (2015) specifically noted that the perspective of PLWH experiencing stigma requires more research because it is not sufficiently described in academic literature. My study would enact Gagnon's expressed need to engage with PLWH to understand how the stigma they experience affects their access to health and social care. Also, my study has the potential to identify new ways of developing inclusive health care settings that promote equitable access to all persons, and

illuminate how community design, transportation, and stigma intersect to create inequities and erect barriers in access to care.

2.5 Problematic Substance Use in Suburban Communities

As the size and spread of suburban communities and the diversity of people with them continues to grow, the presence of substance use – an issue that has traditionally been confined to urban centres – is increasing at startling rates (Draus, Roddy, & Greenwald, 2012; The Canadian Press, 2015; Thorpe, Bailey, Huo, Monterroso, & Ouellet, 2001). The literature explicates that problematic, narcotic prescription use is more prevalent in suburban communities than in urban cores (Draus et al., 2012; Mars, Bourgois, Karandinos, Montero, & Ciccarone, 2014). Although these studies are based in the United States, Carter and MacPherson (2013) acknowledged that prescription narcotics are one of the most commonly used substances by Canadians. Over time, for some, problematic or chronic dependent nonmedical use of prescription narcotics has been shown to evolve into polysubstance and heroin use (Lankenau et al., 2012; Mars et al., 2014; Mateu-Gelabert, Guarino, Jessell, & Teper, 2015). Heroin use, which can include intravenous injection and sharing of drug paraphernalia (e.g., syringes, filters, cookers, etc.), can transmit HIV and other blood-borne pathogens, such as Hepatitis B and C (Akselrod, Grau, Barbour, & Heimer, 2014; Bruggmann & Grebley, 2015). Moreover, Heimer, Barbour, Palacios, Nichols, and Grau (2014) found that injection drug use behaviours are increasing in suburban communities.

The literature has noted that the traditional harm reduction approaches, namely needle distribution programs, to mitigate, address, or reduce harms associated with problematic substance use in urban centres, when applied to suburban communities, are

not as effective and the reasons for this phenomenon are unknown (Heimer, Barbour, Palacios, Nichols, & Grau, 2014; Lamonica & Boeri, 2015). In their comparative interviews with people with problematic substance use in both urban and suburban contexts, Boeri and Tyndall (2012) found that transportation to, and the location of, harm reduction services could be significant barriers to accessing those services. Similarly, Lamonica and Boeri (2015) reported how the community infrastructure found in urban centres to address these issues is not present in suburban communities, which contributes to risky behaviours, such as needle sharing, being undertaken by suburban users. In their study, Lamonica and Boeri further determined that those partaking in problematic substance use had more feelings of despair and isolation in suburban communities and these feelings encouraged increased use. Suburban participants interviewed by Boeri and Tyndall also indicated that they experienced more stigmatization from health care practitioners and other residents in their community, which was another noteworthy barrier to accessing services. As both of these studies (e.g., Boeri & Tyndall, 2012; Lamonica & Boeri, 2015) were conducted in the United States, further research to confirm the degree to which their findings are transferable to Canadian suburban communities is needed. The literature on problematic and chronic dependent substance use in suburban communities additionally illustrates the relationship between community design, transportation, and stigma for PLWH and substance users within suburban communities and how they influence and affect access to health and social care services.

In British Columbia, Marshall, Milloy, Wood, Galea, and Kerr (2012) explained that overdose fatalities with illicit stimulants and prescription drugs are increasing in prevalence in suburban and rural areas, which infers that there is increased access to illicit

substances in some Canadian suburbs. Groft and Robinson Vollman (2007) additionally noted that isolation and despair were common feelings experienced by PLWH in rural Western Canada that were strongly associated with problematic and chronic dependent substance use. These studies offer some preliminary support to the transferability of the findings in much of the literature from the United States, but more research should be done to understand more clearly the reasons why PLWH in suburban communities engage in substance use and what services and supports they need in their communities to support their health and well-being.

2.6 Access to Primary Care and Patient Engagement in HIV Care

Aday and Andersen (1974) provided the most frequently referenced framework for access to medical care. They explained that equity goes along with access to medical care because health policy places more importance on those who do not, or cannot, access care. There are many factors that influence access: population characteristics, such as income, insurance, and attitudes towards care; health human resources and facilities; and wait and travel times. Aday and Andersen also identified that there is a lack of accessible, community-based primary care; much of the primary care that should be accessed in communities is sought in hospital emergency departments.

Almost 40 years later, Jones, Carroll, and Frank (2011) noted the same finding in Alberta: Many Canadians seek care in hospital emergency departments for nonemergent needs because accessible, community-based primary care is largely absent. Many socioeconomically disadvantaged PLWH almost exclusively access care at hospital emergency departments rather than through sustained engagement with a primary care provider (Cunningham et al., 1999), which results in fragmented care that cannot

effectively monitor the progression of HIV. Health care reform to improve access to community-based primary care is an important issue because it focuses substantially more on health promotion, education, and reducing risk factors for chronic or infectious disease development and monitoring the progression of those conditions (Mukhi, Barnsley, & Deber, 2014). Moreover, it is the entrance to the health care system for many patients (Mukhi et al., 2014), and if patients are unable to effectively navigate through the health care system with or without assistance from primary care providers, it is highly likely that they will have unmet health needs. By understanding the barriers and enablers of access to health and social care by PLWH in suburban communities, health systems could be designed in a manner that is more reflective of the needs of many groups within that community who may be marginalized and experience structural inequity.

In Ontario, Kendall et al. (2015) used administrative data to review physician billing records between 2009 and 2012 and found that primary care physicians, rather than infectious disease or internal medicine specialists, were predominantly providing care to PLWH. Additionally, 16 per cent of all HIV-related billed visits during that time period occurred outside of an urban area and no infectious disease specialist ever billed the Ontario government for HIV-related care outside of an urban setting. While these findings are noteworthy, it is important to recognize that the definitions of urban and nonurban used by Kendall et al. were definitions used and created by the Ontario Medical Association (OMA) for physician incentives, recruitment, and retention initiatives (Kralj, 2009). Upon reviewing the work of Kralj (2009), there is a substantial discordance between how many other authors in geography and urban planning (e.g., Gordon & Janzen, 2013; Gordon & Shirokoff, 2014; Moos & Mendez, 2014; Turcotte 2008a, 200b)

and the OMA (e.g., Kralj, 2009) define urban, suburban, nonurban, and rural communities. Numerous communities in the Durham, York, and Peel regions that would be considered suburban by geographers and urban planners are classified by Kralj and the OMA as urban. Thus, there is ambiguity in the health services literature depicting where PLWH in Ontario reside and how they access health and social care within their community. One of the strengths to my research approach is that it is transdisciplinary. I am drawing literature across different disciplines (e.g., health services and policy, geography and urban planning, sociology, and psychology), which could provide greater clarity to understanding Canadian suburban communities and how care is accessed within them by PLWH.

Additionally, Kendall et al. (2015) found that over 75 per cent of the primary care physicians caring for PLWH graduated from medical school before 1990 and cared for five or fewer PLWH in their practice. With such a low proportion of PLWH in a given physician's practice, it is possible that physicians may not keep themselves current with the advances in HIV treatment. This could result in suboptimal care received by PLWH, or it could result in PLWH being referred to infectious disease or internal medicine specialists that are located outside of the community in which PLWH reside. The latter would underscore whether PLWH are able to travel to the specialist and access that care; it also calls into question the manner in which medical specialists are distributed within provincial health care systems to ensure equitable access to these important services for all segments of the population. Furthermore, many of the primary care physicians identified by Kendall et al. have been in practice for more than 25 years and may be nearing retirement. It is conceivable that when these primary care physicians retire, the

PLWH for whom they cared may experience delays or gaps in the continuum of their care. Considering the stigma that many PLWH experience in health care settings and how it produces delays in care or gaps in their care history (Magnus et al., 2013), ensuring that PLWH are engaged and empowered in their care by their health care practitioners is exceptionally important.

Mugavero, Norton, and Saag (2010), and Risher, Mayer, and Beyrer (2015) discussed the continuum of care for HIV: screening/testing, counselling, access to antiretroviral medication, and follow-up care. The authors of both articles reiterated how access and patient engagement are essential for accomplishing culturally-competent care and facilitating the continuum of care for HIV. However, it is observed that the PLWH population, particularly the men who have sex with men segment, is now widely dispersed across geographies and the services that were once concentrated in areas where they congregated have not evolved with this population's migration pattern (Carman et al., 2010; Eberhart et al., 2014). This makes it especially challenging to engage with those who utilize, require, or benefit from the service, and thus providing relevant, accessible, and high quality services based on need becomes increasingly difficult. While Mugavero et al. and Risher et al. addressed many factors related to health systems and services in the United States, it is important to note that engaging with patients and incorporating their perspectives and experiences to inform health policy, services, and practices should be a universal goal of all health systems. Considering how there is a gap in the literature related to PLWH in suburban communities, particularly in Canada, my study would close this gap and establish the extent of transferability of the findings above.

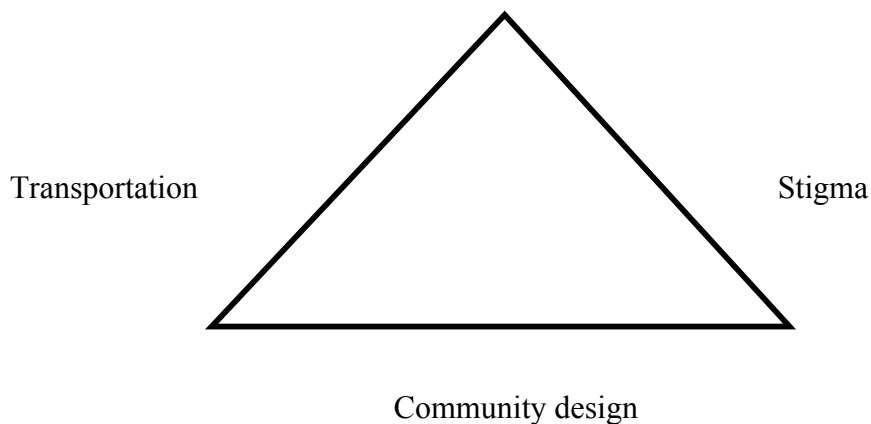
2.7 Conceptual Framework

A conceptual framework to analyze the interview data was developed from my reflections on the literature consulted during the development of the inquiry. With respect to community design as a factor that influences access to care, many authors (e.g., Forsyth, 2012; Gordon & Shirokoff, 2014; Moos & Mendez, 2014; Turcotte, 2008a) confirmed that suburban communities are a prevalent form of community in Canada and internationally, yet a precise and universal definition of a suburban community is absent from the literature. This highlighted the need to perform research that investigates how suburban community design affects health and social care service access. In addition, there were no studies conducted on PLWH living in a suburban community in Ontario, Canada.

The body of literature related to transportation and its effects on health service utilization (e.g., Silver, Blustein, & Weitzman, 2012; Syed, Gerber, & Sharp, 2013; Turcotte, 2008b) indicated that this is another factor that should be investigated. The need for a car was a prevalent theme, and it was also associated with access to care. Many of these studies were conducted outside of Canada and in the United States, which underscored the need for exploratory research to be performed domestically to confirm or refute the transferability of their findings. As PLWH may be socioeconomically disadvantaged (e.g., receipt of ODSP and/or other financial sources of support from the government) and not own their own car, it is necessary to understand how various modes of transportation affect their access to health and social care services in a suburban, Ontario, Canada community.

HIV stigma is a major public health challenge that has persisted since the discovery of HIV in the 1980s (Chambers et al., 2015). Despite numerous advances in the biomedical understanding of HIV, its transmissibility, and treatment regimens, all of which have been broadly disseminated, findings in the literature affirm that PLWH in low HIV prevalence communities continue to be highly vulnerable to stigmatization (Zukoski & Thorburn, 2009). Therefore, community design, transportation, and HIV stigma intersect and may likely contribute to how PLWH in Canadian suburban communities access care.

Figure 2-1: *Conceptual Framework*



2.8 Moving Forward: Creating Healthier Communities and Health Care Systems

The literature reviewed in this chapter illustrates how community design, transportation, and stigma intersect in multiple ways to influence or shape health inequities for PLWH in suburban communities across Canada. Because suburban living is highly prevalent among Canadians, it is necessary to investigate, understand, and dissect the relationship between a person's environment and access to health and social care. Moreover, multiple authors (Deber, Gamble, & Mah, 2010; Fieldberg, Vipond, & Bryant, 2010; Low & Theriault, 2008) expressed how health care is being shifted into

communities from hospitals and central institutions of care. Therefore, understanding: (1) How suburban PLWH access health and social care services; and (2) How the structure or design of the suburban community influences and affects the access of PLWH to those services becomes even more important and relevant to the sustainability and development of healthy communities and health care systems.

Chapter 3: Methods, Data Collection and Analysis

In this inquiry, I sought to understand, describe the experience of, and offer insight into: (1) How do PLWH access health and social care services in a suburban, Ontario, Canada community; and (2) How does the structure, design, and population demographics of their suburban community influence and affect their access to health and social care services? To answer these questions, the AIDS Committee of Durham Region (ACDR) was contacted to assist with participant recruitment. As the principal investigator, I also reached out to colleagues in my professional networks who knew of PLWH who would be interested in speaking about their experiences accessing health and social care. I conducted in-depth interviews with PLWH using hermeneutic phenomenology associated with Martin Heidegger (see Dowling, 2007; Lavery, 2003; Todres & Wheeler, 2001) to understand and describe their experience of accessing health and social care services. In this chapter, I present the ethical considerations, research study design, setting and participants, and data collection and analysis procedures used to conduct this inquiry.

3.1 Ethical Considerations

3.1.1 Research Ethics Board Approval

This inquiry (REB # 15-112; see Appendix A) was approved on March 16, 2016 from the Research Ethics Board at the University of Ontario Institute of Technology.

3.1.2 Protecting Co-Participant Confidentiality

Co-participant confidentiality was protected through a few different strategies. First, the study was almost entirely paperless, which ensured that PLWH were not recording any personal identifiers, such as name, email address, telephone number,

among others, on paper that could be lost, viewed, or accidentally accessed by any unauthorized person at a later date. Second, co-participants used a pseudonym of their choosing during the interview; this protected their real identity. Additionally, co-participants were instructed to not use the real names of others during their interview, which provided another layer of confidentiality and anonymity in describing the experience of accessing health and social care services while residing in a suburban community. Third, a code key was created in Google Sheets on Google Apps for Education (UOITnet server) that contained the co-participant's name, pseudonym, email address, and transcript link. Only I, the principal investigator, had access to this code, and it was securely deleted from the UOITnet server once the co-participant no longer needed to confirm meaning in their statements or add further descriptive information on their experience. At that point, their interview transcript became entirely anonymized, which guaranteed co-participant confidentiality.

3.1.3 Obtaining Consent

Co-participants received a printed letter of invitation and consent package that outlined the study (see Appendix B). Verbal consent was captured within the interview transcript by reviewing the consent statement and answering any questions. This approach also helped to safeguard co-participant confidentiality because their real name or any other personal identifier was not written down and linked to their participation in research related to living with HIV, which could have resulted in a loss of anonymity and stigmatization (see Chapter 2: Literature Review for further information on HIV stigma).

3.2 Research Design

3.2.1 Rationale for Social Constructivist Paradigm and Qualitative Methodology

The primary research aim of this inquiry was to explicate the experience that PLWH have in accessing health and social care services within the suburban community in which they live. This is an irrefutable component of a research question that would be addressed in a social constructivist, or interpretivist, research paradigm (Gergen & Gergen, 2008). No two people would have the same experience accessing health and social care services while living with HIV in a suburban community because there is an infinite combination of personal, social, and economic factors that would influence their respective experiences. In other words, the sum of a person's life experience shapes the meaning they derive from their world, and thus this meaning will differ between people (Lavery, 2003). This perspective additionally supports the placement of this inquiry within the social constructivist research paradigm.

Because social constructivism affirms that there are multiple realities, which is an opposing view to positivism (Giacomini, 2010), the use of a quantitative methodology would be inappropriate when working within this paradigm. Qualitative research methodologies focus on interacting with their population of interest and use inductive reasoning (Neutens & Robinson, 2010; van den Hoonaard, 2015; Yin, 2016). Many authors (Bourgeault, Dingwall, & de Vries, 2010; Bowling, 2014; Neutens & Robinson, 2010; van den Hoonaard, 2015; Yin, 2016) identified common characteristics of qualitative approaches: searches for meaning in a person's life as lived under real conditions and represents their perspectives; is open-ended, descriptive, and flexible in its

design; and explains context. In light of these characteristics and the aims of my research questions, the selection of a qualitative approach is further reinforced.

3.2.2 Phenomenology

Phenomenology is an important qualitative research methodology for health researchers. It focuses on understanding the human experience and the experiences that people have, which conveys important human dimensions that ultimately improve and ameliorate the delivery of services, such as those within health and social care (McWilliam, 2010). Phenomenology originated with Edmund Husserl (1859-1938) who aimed to describe and explain specific experiences or phenomena (Lavery, 2003; Mackey, 2005; McWilliam, 2010; Reiners, 2012). Husserl's approach to phenomenology, which is also known as transcendental or descriptive phenomenology (Adams & van Manen, 2008; McWilliam, 2010), focuses on the consciousness of an experience and requires researchers to bracket or set aside their assumptions, values, and beliefs to understand the essence of the experience under investigation (Adams & van Manen, 2008; Reiners, 2012). The use of bracketing in phenomenology embraces more of a positivist stance (Lavery, 2003) and, as a result, would not adhere to the values of the social constructivist paradigm.

Martin Heidegger (1889-1976) worked with Husserl, but disagreed with aspects of his approach to phenomenology (Dowling, 2007; Todres & Wheeler, 2001). Heidegger acknowledged that consciousness is a part of the experience, but not the primary focus of it (Lavery, 2003). He placed more emphasis and focus on the life world or how an experience is lived by a person (Lavery, 2003; Reiners, 2012). As a result, Heidegger's approach to phenomenology aligns itself with social constructivism because a person's

perceptions are directly linked to their experience, and the researcher does not bracket their experiences (McWilliam, 2010).

Collaboration with research participants is important to the hermeneutic or interpretive process. Part of the researcher's role is to clarify the meaning in the participant's experience, or the phenomenon being studied, to ensure that it has been described as accurately and in as much, rich detail as possible (Kelly, 2010; McConnell-Henry, Chapman, & Francis, 2009). Moreover, as the researcher's assumptions, values, and beliefs are not bracketed and excluded from the research (Giacomini, 2010; Lavery, 2003; McConnell-Henry et al., 2009; McWilliam, 2010), it makes the researcher a participant to the process and supports the notion of co-participation. Thus, the term *co-participant* is used through this research because the researcher and the participants each have an active role in co-constructing knowledge on the experience of living with HIV in a suburban community and accessing health and social care services. For example, in this study, I, as the researcher and principal investigator, would actively journal and reflect upon my journey, thought process, and experiences interacting with co-participants to help describe the phenomena and answer the research questions.

3.3 Setting and Co-Participants

3.3.1 AIDS Committee of Durham Region (ACDR)

The ACDR is a not-for-profit and charitable organization that provides HIV prevention education, harm reduction services, and a multitude of health and social services (e.g., medical and allied health therapies, counseling, food bank, etc.) to support PLWH in the Durham region (AIDS Committee of Durham Region, 2016). The ACDR provided a letter of approval (see Appendix C) on February 4, 2016 for this inquiry, as

per the ethical review requirements outlined by the Research Ethics Board at the University of Ontario Institute of Technology. This letter additionally stipulated that the ACDR would actively recruit co-participants and provide a space for the interviews to occur. The ACDR required that I, as the researcher and principal investigator, sign their confidentiality agreement that all staff and volunteers sign during their orientation to the organization and adhere to their code of conduct while performing my research on their premises.

3.3.2 Inclusion and Exclusion Criteria

To participate in this inquiry, co-participants needed to be: (1) Living with HIV in a suburban community within the Durham region (see Chapter 2: Literature Review for further information on suburban communities); and (2) 18 years of age or older. Any person not living with HIV, under the age of 18, and living in a community considered to be urban or rural outside of the Durham region was ineligible to participate.

3.3.3 Recruitment Strategy

Co-participants were recruited by one of two methods: (1) Verbally by staff at the ACDR, or (2) Through snowball sampling. When a staff person at the ACDR verbally recruited a possible co-participant, the co-participant was directed to contact me, the principal investigator, by email for further information on the study if they were interested in participating (see Appendix D for the verbal recruitment script provided to ACDR staff and Appendix E for the verbal recruitment script provided to my networks). This approach was selected so the ACDR staff and people in my networks remained at arms-length from the recruitment process and co-participants did not feel coerced into participating. Their decision to seek further information on the study or participate in it

was at their sole discretion, which guaranteed their autonomy and anonymity. ACDR staff were not advised of who reached out to me for more information or the true identities of the co-participants. People in my, the researcher's and principal investigator's, networks external to UOIT who were aware of my research and population of interest – PLWH in a suburban community within the Durham region – reached out to possible co-participants in their networks and connected them with me by email, thereby employing snowball sampling (Bowling, 2014; van den Hoonaard, 2015). Similar to ACDR staff, people in the principal investigator's external networks were not advised of who enrolled in the study.

Co-participant recruitment and data collection occurred in May, 2016 through until August, 2016. When a possible co-participant contacted me, the principal investigator, via email, I determined their eligibility to participate and enroll in the study. If the co-participant decided to enroll, I asked for dates and times when the co-participant could meet me at the ACDR or a mutually agreeable location to conduct the interview. If the interview was to be held at the ACDR, I notified the ACDR staff contact person of the co-participant's availability and determined when it would be convenient for me to have access to a private room where the interview could be conducted. In both cases, I advised the co-participant via return email of the confirmed date and time when we would meet.

According to Lavery (2003), inquiries that use phenomenology should continue to conduct interviews until the experience under investigation has been captured in such explicit detail that no new descriptions are elucidated by co-participants, thereby reaching

data saturation. Bowling (2014) asserted the same position: Once no new findings emerge from conducting interviews, an appropriate sample size has been achieved.

3.3.4 Sampling Procedures

As ACDR staff and people in my networks directed any PLWH who met the inclusion criteria and expressed an interest to learn about the study to contact me, opportunistic sampling, which is a form of convenience sampling, was employed (Bowling, 2014; Kelly, 2010). The exploratory nature of this inquiry to describe and understand the experience of accessing health and social care services while living with HIV in a suburban community dictated that any person who was eligible and willing to participate should be afforded the opportunity. This position is consistent with van den Hoonaard (2015) regarding the manner in which qualitative research projects should select their sample. Furthermore, the research questions do not explicitly cite a specific group of PLWH (e.g., people who inject drugs, men who have sex with men, immigrants from countries where HIV is endemic, etc.). This was a purposeful distinction to ensure that any PLWH who met the established inclusion criteria – regardless of the manner in which that person acquired HIV – would be eligible to participate in order to gain a variety of experiences, which is also recommended by Lavery (2003) regarding co-participant selection. Subsequent research could focus exclusively on one of those groups and the specific nuances of their experiences in accessing health and social care services while living in a suburban community.

3.4 Data Collection

3.4.1 In-Depth Interviews

The in-depth interview is one of the most frequently used tools for data collection in qualitative research (van den Hoonaard, 2015; Yin, 2016). Kelly (2010) explained that the semi-structured format produces substantial, rich textual data that cannot undergo statistical analysis, and that analysis would be one of the main objectives of using a structured interview format. Furthermore, the structured interview format is not well suited to exploratory research because it predominantly contains close-ended questions (Kelly, 2010; van den Hoonaard, 2015; Yin, 2016). Hence, in this research, I used the in-depth format because it was important to probe into the specific and minute aspects of the co-participant's experience, which occurred in the moment during the interview (Bowling, 2014; Kelly, 2010; Yin, 2016). Furthermore, the open-ended nature yielded substantially more textual data that assisted in helping to describe and understand their experience of accessing health and social care services within a suburban community. It was essential that the tools used to collect data were aligned with the chosen research paradigm and methodology because they all built upon each other to create a cohesive research protocol.

The interviews were conducted at the ACDR or a mutually agreed upon location. Co-participants were advised that they need only answer questions to which they were comfortable providing an answer (see Appendix F for the Interview Guide). Interviews were 30-60 minutes in length; interview questions elucidated their experiences accessing health and social care services within a suburban community (e.g., experiences with health care practitioners and their care, influence of transportation on their access, etc.).

3.4.2 Data Storage and Management

I recorded the interviews on a digital recorder and transcribed them verbatim in Google Docs on the UOITnet server. Once each interview was transcribed, the audio recording on the device was deleted. Data on the UOITnet server is encrypted (Google, 2016a) and complies with the U.S *Health Insurance Portability and Accountability Act* (Google, 2016b), which affirms that it is an established medium in which sensitive health data can be safely stored.

There are many benefits to housing research data online versus on an encrypted USB drive or in a hard copy format kept in a locked cabinet or location. First, the likelihood of the data being lost, misplaced, or stolen is low. Online storage ensures that the data is available via an internet connection to only the person, or owner of the data, whose account in which it is stored (Google, 2016c). In addition, it is unlikely that the data will become corrupted because it is encrypted and securely housed on multiple servers in different locations (Google, 2016b). This also protects the integrity of the data for its analysis.

Second, data access can be customized through the utilization of the “share” function. For example, shared access can include the ability to view, comment, or edit, and additional people can be easily added or removed by the owner of the data or document being shared. Moreover, the document owner can restrict collaborators from sharing it with others, and can disable the functions to copy, download, and print the document. This was a particularly useful and efficient strategy for collaborating with co-participants so they could review their interview transcript and confirm meaning in their statements or add more information to describe their experience as they felt appropriate

and necessary. Additionally, all changes to the transcript are tracked automatically in Google Docs, which adds another layer of protection for the data. This collaborative, online approach also facilitated member checking (Yin, 2016). Further, it protected the sensitive content of the interview and reinforced the protection of co-participant confidentiality.

Third, as the data was only able to be retrieved by logging into the UOITnet server, conducting data analysis was not confined to a particular location that had specific operating hours (Google, 2016d). This was a huge benefit in maximizing productivity and remaining within predetermined project completion timelines.

3.4.3 Researcher Experience

Regular, reflexive journaling of my, the researcher's and principal investigator's, journey throughout the research process was important to: (1) Review my current position in relation to this research; (2) Assess the evolution in my assumptions, values, and beliefs about my research questions; and (3) Keep track of emerging patterns or themes and interpretations of the co-participants' lived experiences for the analysis of the in-depth interviews. Moreover, reflexive journaling is a central tenet of hermeneutic phenomenological inquiry associated with Martin Heidegger (Laverty, 2003; Mackey, 2005). During the development of this research, I would journal why it was important to me to describe this phenomenon, and these entries also affirmed my passion and desire for creating access to services that support and facilitate health. Before I met with a co-participant, I wrote down, in a separate Google Docs file on the UOITnet server, my thoughts, feelings, and assumptions about what might transpire and how this specific experience would contribute to the inquiry. Following the meeting, I reflected upon my

interaction with the co-participant, salient points from our discussion, and how this experience informed how I thought about – and moved forward with – this research. I also created entries while performing transcription of the interviews to memo important codes for my analysis. Entries were also created before and after I immersed myself into the analysis of the data contained within the interview transcripts and when I reviewed literature pertinent to my inquiry. It was important that I journal at these times to help refine the direction of my work and keep me grounded in my research questions. Furthermore, these reflexive entries permitted me to focus my thoughts and identify common themes about the experience of accessing health and social care in a suburban community for PLWH.

3.5 Data Analysis

3.5.1 Data Analysis Procedures

Yin (2016) and van den Hoonaard (2015) identified key phases for qualitative data analysis: organizing the data; coding; establishing patterns and metathemes; and synthesizing the data with literature to explain it. It should be noted that while these phases appear to follow a sequential, linear process with each one building upon its predecessor, that is not the case. The process is highly iterative and cyclical, often requiring work to be done simultaneously in more than one phase.

In this research study, first, co-participants reviewed their interview transcript to clarify their meaning and add any additional information on their experience as they deemed necessary. This cyclical process occurred as often as the co-participant desired. This approach could be regarded as member checking (Yin, 2016) because the co-participant is the expert of their experience, and having them affirm their language to

describe their experience supports the validity of the findings. Once this was complete and all the interview transcripts were organized, I reviewed my reflective journal entries about these interviews and my research process to ensure that my experience and thoughts were also captured in rich detail. In addition, the transcripts and my reflective journal entries were grouped by co-participant and their interview date; reflective entries pertaining to the research process were chronologically sequenced.

All interview transcripts and reflective journal entries were exported into NVivo for Mac, version 11.2.1. As the principal investigator, I regularly read the interview transcripts and my journal entries and coded the data within NVivo. Coding is the process by which themes are assigned to the data (van den Hoonaard, 2015; Yin, 2016). Coding started with the most obvious and overt findings and progressively evolved into creating higher level categories and merging themes and patterns. For instance, I coded each line of every transcript. Once this was complete, I performed another analysis and determined which codes were similar and could be combined into one. This process was repeated, each time creating higher order categories and codes that captured the themes of the experience of living with HIV and accessing health and social care services in a suburban community.

Establishing patterns and metathemes required the rearrangement of data and codes into a matrix (Yin, 2016). This matrix took the form of a data audit trail (Rodgers, 2008; see Appendix G), which illustrated how co-participant statements were linked to their first codes, to their categories, and then grouped into the appropriate metathemes. Finally, synthesizing the data with the literature entailed performing a comprehensive review of studies and literature from key health sciences databases (e.g., Web of Science,

Scopus, CINHALL, and PubMed) that further spoke to and substantiated the findings I gathered from my data. In this phase, van den Hoonaard (2015) also recommended to establish how the metathemes were related, which was done through continually utilizing my conceptual framework (see Chapter 2: Literature Review).

3.5.2 Evaluating Authenticity and Trustworthiness

The two main criteria used to evaluate research performed within a social constructivist research paradigm are authenticity and trustworthiness (Lincoln & Guba, 2000; Patton, 2008). Authenticity in qualitative research is defined as being representative of the population under study (i.e., PLWH), and it also facilitates trustworthiness (James, 2008). Thus, authenticity is present because any PLWH who met the inclusion criteria could enroll. Furthermore, authenticity, as per the definition from James (2008), requires that the broader social and political implications be considered. In my research, this was accomplished through the utilization of suburban community definitions and insights from geographers and urban planners, rather than framing suburban communities according to the Rurality Index of Ontario (RIO) (Kralj, 2009).

Given and Saumure (2008) explained that trustworthiness in qualitative research is evaluated through an examination of credibility, transferability, confirmability, and dependability. Credibility, which requires a detailed and accurate description of the phenomenon of interest, is present in this research process because reflective journaling and a data audit trail were included in my analysis to substantiate my findings. There are other chronic health conditions that are stigmatized and present among those living in suburban communities, such as developmental disabilities, problematic and chronic dependent substance use, among others, which confirms how the inquiry is transferable to

other contexts. Confirmability and dependability refer to the data supporting the interpretations and the extent of transparency in the research process. These criteria were achieved through preserving the integrity of the interview and reflective journal data by housing them within the UOITnet server, compliance with the research protocol outlined in this chapter, and adherence to ethical standards of research involving humans. Furthermore, only results that are linked to the interview transcripts and my reflective journal entries are presented in the following chapter, which can also be reviewed in the data audit trail.

3.6 Study Strengths and Limitations

One of the strengths to this study is that it is the first to perform in-depth interviews with PLWH within a suburban community in Ontario, Canada to understand their experience of accessing health and social care services. Second, through the interpretation of significant statements made by co-participants, an understanding of how to improve the patient experience for PLWH, specifically in terms of patient engagement, coordination and delivery of services, and patient-centred care, is captured. The study design is strengthened through working collaboratively with a local AIDS service organization, the ACDR, and through leveraging my professional networks to connect with PLWH in a suburban community.

In terms of limitations, because phenomenology depends on co-participants to clearly articulate and provide rich details of their experiences, the findings are limited to the extent of detail that the co-participants chose to disclose due to their comfort level or extent of vocabulary. Additionally, co-participants may be subject to recall bias when providing accounts of their experiences, especially if the experience did not occur within

the same time frame as their interview. To address it, all co-participants had an opportunity to review their transcript and clarify their statements to ensure that their experiences were correctly captured.

Chapter 4: Results

This chapter presents the results gathered from the in-depth interviews conducted with PLWH about their experiences accessing health and social care services while residing in an Ontario, Canada suburban community. There were six prevalent themes arising from their experiences: fear of disclosure and stigmatization; personal and unintentional biases about HIV; isolation; transportation, cost and time: barriers to access; flawed delivery of health care services; and inefficient, antiquated social care service delivery.

4.1 Co-Participant Demographics

Table 4.1 provides the demographics of the co-participants ($N = 13$) interviewed in this inquiry. Most of the co-participants were in their 40s ($n = 6$) and male ($n = 9$). Almost all of them resided in Oshawa, Ontario ($n = 12$) and sexual orientations were split between heterosexual ($n = 6$) and homosexual ($n = 6$); one co-participant identified as asexual. A significant proportion ($n = 8$) of the co-participants were not employed and received disability and/or social support from the government. Others were employed either in a full-time or part-time capacity ($n = 3$) or were retired ($n = 2$). Most co-participants identified some form of substance use, primarily alcohol and marijuana ($n = 7$), but narcotics and crystal methamphetamine were also identified as substances consumed ($n = 3$). Moreover, there were co-participants who identified as having an Aboriginal ancestry ($n = 3$) or immigrating to Canada from a country where HIV is endemic ($n = 3$). Thus, there is a range in the demographics of the co-participants interviewed, which captures an array of experiences of what it is like to live with HIV in a suburban community and access health and social care services.

Table 4-1: Co-participant Demographics

	N = 13	%
Age		
> 60	2	15
50-59	4	31
40-49	6	46
30-39	1	8
Gender		
Male	9	69
Female	4	31
Suburban Community		
Oshawa, Ontario	12	92
Ajax, Ontario	1	8
Employment		
Yes (full or part-time)	3	23
Retired	2	16
No (receives disability/social support)	8	61
Sexual Orientation		
Heterosexual	6	46
Homosexual	6	46
Other	1	8
Aboriginal Identity		
Aboriginal	3	23
Non-Aboriginal	10	77
Immigration from a Country Where HIV is Endemic		
Yes	3	23
No	10	77
Substance Use		
Alcohol (occasional)	6	46
Alcohol (dependent)	1	8
Marijuana	3	23
Other	3	23

4.2 Fear of Disclosure and Stigmatization

Fear of disclosing their HIV status was a central theme in this study. Generally, PLWH in this suburban community were concerned regarding how they would be treated if others, including health care professionals, knew of their seropositivity. Many PLWH

also identified how they were stigmatized by family, members of their community, and health care practitioners.

4.2.1 Fear of Disclosure

Many co-participants feared disclosing their HIV status or withheld it from carers.

One co-participant said:

But I don't freely share it with a lot of people. I would say out of my friends, maybe 10 per cent of the people know. My neighbours don't know. People around me don't know. I have volunteers who come to my home and help me out and I don't tell them.

In this instance, the co-participant admitted that he keeps his HIV status a secret. This secrecy highlights the burden of living with HIV because of the stigma that accompanies it. Similarly, another co-participant expressed similar sentiments:

We're a low profile – we're just your normal people. On the street, people think that [he] and I are brothers. They met our mom and dad, and why tell them anything different, if that's what they think. [He] and I both look alike, we're both basically the same age, and if they were to ask, I'd say I was adopted, simple as that.

In this instance, the co-participant spoke about perceptions of being gay, living with another man, and living with HIV. His desire to leave inaccurate perceptions that others have in his community in tact propagates a false narrative about his life and living arrangements; it also demonstrated how a fear of disclosure was prevalent for PLWH within a suburban community.

Another co-participant explained how he feels about disclosing his status in health care settings:

But, yeah, it's, I guess it's because I'm afraid of – my understanding is that you have to disclose, and there's a form, if they use a standardized form – the last one I filled out in Toronto asked specifically about HIV. Different people have suggested to just ignore the question, don't answer, don't disclose.

This quote illustrated how the co-participant's fear of disclosure was related to his seropositivity. He also alluded to a culture among PLWH in this suburban community that avoids the disclosure of their HIV status within health care settings. Another co-participant identified similar sentiments: "Most times you don't even want to disclose. I usually wait until I'm in the room with the doctor, personally, instead of telling the receptionist or writing it out, and then I let them know." The reservations that PLWH in this suburban community had about being candid with their HIV status to health care practitioners substantiated fear of disclosure and was thus a barrier for accessing health care services.

In the following quote, the co-participant explained how decreased anonymity in health care settings made it challenging to seek HIV-related care services:

Similarly, going to the Positive Care Clinic, I've run into friends and acquaintances who definitely don't know my HIV status...yet they serve as volunteers at the Lakeridge Health building. To my knowledge, the only other health services available at this location are rehabilitative, which I clearly wasn't in for. So, in such a circumstance, have I again outed my HIV status? I think anonymity in Durham can be harder to preserve.

Another co-participant identified her fear of being on antiretroviral medications and having her roommates know that she lives with HIV:

I was sharing a condo with some friends and I was poz [seropositive] and I wasn't on meds yet. And I was thinking that I hope I don't have to go on the medication that you have to store in the fridge because then they would know. So the thing was, when I got so sick, I had to try and hide it.

For this co-participant, the possibility of being on medication posed a threat to the secrecy attached to her seropositivity; disclosing her HIV status was a source of profound fear and anxiety.

4.2.2 Lived Stigmatization

HIV stigma was experienced by many co-participants. One co-participant spoke about how the stigma within their small, suburban community created a paranoia whereby PLWH would avoid seeking services that were related to living with HIV and therefore would travel into a larger, urban centre for creating a sense of community and accessing care:

It may be still because they don't want to be identified coming into this building or going to pride, say, or anything to do with anything local – it's still a small town here, even though we're GTA. They like to go to Toronto on the weekends and carry on.

Another co-participant identified how many homosexual men did not want to be associated with any organization or group linked with HIV because of the stigma that accompanied living with HIV in their suburban community:

No one else responded, and I was told: 'We have tried in previous years, at ACDR, to get gay a men's group. We get two or three guys interested and it peters out. And the reason is: a lot of men don't want to be seen going to ACDR.' So our groups were amalgamated and they had it offsite.

In a similar vein, another co-participant spoke about how he is stigmatized within retail or public spaces in the following: "Little smirks or something in the store. Somebody will look at you funny or something. A redneck or something like that." Moreover, he spoke derogatively about people who stigmatize, which further illustrated a lack of community cohesion and increased opportunities to stigmatize others on the basis of differences in opinions, appearances, etc.

A female co-participant spoke about how she was stigmatized by her family and others in her suburban community for living with HIV:

My older sister broke my heart. She told people living in that building who are nothing but welfare mentality, uneducated – started a petition that went like

wildfire trying to have me kicked out of this town. There was over 10,000 signatures in less than a week. I couldn't even go outside my door. People were throwing eggs at my house. It was bad. You think any of the neighbours that live here, ok there's been a few families move in that weren't here, but everyone else remembers. They don't even – I could sit outside and my neighbours, the ones that don't know, they'll speak to me, and the ones that do know, if they see them talking to me, they'll say: 'Oh don't go near her, she's got HIV.'

Similar sentiments regarding stigma within the suburban community were expressed by another female co-participant:

I still feel there is so much ignorance and I still feel there's so much blame. That's the part that's sad because people don't know how you got infected, but there's still the question of 'How did you get that?' and other stuff.

These two quotes further substantiated how PLWH were stigmatized in their suburban community. They illustrated how the stigma of living with HIV shamed them and prevented them from being included within their community.

4.2.3 Intersecting Stigmas

Two co-participants identified how intersecting stigmas, such as sexual orientation and the presence of other communicable infections (e.g., Hepatitis C), influenced their access to care:

Well, I don't mind people knowing right away that I'm gay, but it's just trying to get the HIV, Hep C out of my mouth. Because if I do that, people want to beat the crap out of me, do this and that to me, treat me like garbage. It saddens me. It really does. It pisses me off that, you know, it's a new millennium and people should not be that paranoid and scared of HIV and Hep C.

Another co-participant also believed that his sexual orientation was a significant barrier to receiving timely and appropriate care. "If I wasn't gay, I wouldn't have any problem whatsoever. There's a 99 per cent chance I wouldn't have any of the problems I've had with regards to being HIV positive." Another co-participant identified how he

encountered indirect stigmatization that intersected with his lifestyle and family composition:

Whereas the doctor who had given me those forms, it wasn't so much a – my interpretation wasn't so much as a, like a response to the HIV, but a response to – he asked me some personal questions, like the icebreaker sort of questions: 'You're married?' 'Yes, I'm married.' 'Do you have kids?' 'Yes, I have a son.' 'How long have you and your wife been together?' That kind of stuff. So then we got more shifted to – he did the examination and conversation shifted to more medical questions, one of them was anything he should be aware of. I said: 'Well, you should know that I'm HIV positive.' So he kind of did that double check and said: 'But you're married.' 'Yes, I'm married.' So then he says: 'So how did you get HIV?' ... It clearly illustrated a 'how can you be married to a woman and have caught HIV?' But again, it's not a question you would expect to be faced with from a doctor. It felt kind of intrusive, or more that he was making interpretations. And ultimately how I contracted the virus really doesn't matter to what precautions he needs to take as a doctor, right? Whether I contracted it through MSM or through a blood transfusion or whether I contracted it through needle use, what he needs to do as a doctor is the same, right?

HIV stigma intersected with many factors, such as gender, sexual orientation, and comorbidities. This finding confirmed that intersecting stigmas experienced by some co-participants living with HIV in this suburban community were a barrier to care.

4.2.4 Pharmacies

Pharmacies were identified as a health care setting where PLWH encountered stigmatization, unease, and fear. "When we first started getting HIV drugs up at the Loblaws pharmacy there, the first time was like: 'What's going to happen?' ... I've heard stories of people having some trouble with attitude and stuff." Other co-participants expressed how picking up their medications from the pharmacy created much anxiety:

I was terrified because I was so scared. You know how sometimes the pharmacist calls you to the counter when your meds are ready and then: 'Oh, have you taken this before?' And then when you say no, they start reading what could happen and the drug's name is so and so, and I was so terrified the first time I filled my prescription. Oh my God, oh my God, I was just hoping please don't do that, please don't do that. And it just so happened that when she called me up I was the only person there, but knowing that I had this fear.

Additionally, pharmacies were places that could reveal a lot about a person's health and their health information. For instance, any person within the pharmacy or pharmacy area could overhear the names of medications being dispensed to some other person, if the pharmacist did not provide their consultation in a private area. "It doesn't give you much privacy. Even if they didn't know what they were mentioning about my meds."

Another co-participant identified how his HIV status and health information were publicly disclosed in the pharmacy:

I thought about maybe changing my medication and having it all go there, it's closer to my house. And I thought I might do that. It's a brand name pharmacy – the biggest one there is. And the pharmacist just kind of shied away from me when he found out what kinds of medications I was on and started asking questions out loud: 'What's your count? When did you get HIV? How long have you had HIV?' There's customers around and he's supposed to be keeping this quiet. You don't do that. You don't talk loud about things that are supposed to be confidential. And it even says confidential area and he's loudly saying: 'And how long have you had HIV? What pills are you on? What's your count?' And he was just so obnoxious, but I didn't tell him: 'Enough's enough, you're being too loud.' He wasn't shy about it at all. 'Oh you're on a lot of different medications? What are you on all this stuff for? What are you on this here for? And why do you do that, what's the problem here?' He didn't take me into a room or nothing; everything was done out in the open and there's people behind me. He yelled: 'HIV' and: 'How long have you had HIV? AIDS!' And I'm just like: 'Oh God.'

Another co-participant said how he was overtly stigmatized by the pharmacist at a local pharmacy within his community:

I was in one pharmacy and getting a full complement of meds filled – so my HIV meds, my antidepressants – and I was actually told to go get my prescriptions filled elsewhere. They didn't volunteer a reason why, nor did I ask because it was so surprising. The easiest interpretation of that is one of stigma or something akin to that. But again, that's just an interpretation, right? And like I say, the easiest interpretation of being sort of told to get your prescription filled elsewhere, you do this double-take and move to: 'Well, was I behaving in a way? Am I so –' I think I present as a quiet, unassuming – I'm not an aggressive person, but you start to wonder: what's going on? Am I misinterpreting? Is my body language saying something different? You know? You really start to question what's going on. But the easiest interpretation is that they weren't comfortable with me as a

client, whether it was for mental health – the antidepressants, or the HIV meds. Those are the only two things that I could see, so definitely you're not going to go back and subjugate yourself to that again, no.

The following co-participants additionally stated how suburban pharmacies were not always stocked to dispense HIV antiretroviral medications:

They just didn't have what I always needed. I used to deal with the one in my family doctor's building, but they were of the same nature. And I didn't like them to talk openly about it, in front of everybody.

The pharmacy in St. Catherine's was like: 'Oh, it'll be no problem.' It was actually recommended by the agency in St. Catharine's, in Niagara, because everyone fills their medications there. And after getting there, they would over order one of my medications. So I would have two months back up on one, and I'd run out of another within that two-month period that they're over with. And they wouldn't sit down and talk to me and say: 'Ok, what do you need to make sure that all of them need to be at the same level?'

These two quotes evidenced the stress of trying to get antiretroviral prescriptions filled. Moreover, it showed that within the suburban community it is more challenging to treat and manage HIV and/or other health conditions because pharmacies were not fully equipped to dispense the medications needed for those conditions. For PLWH, this was a barrier to receiving an appropriate continuum of care from their treating clinician. Also, considering the importance that antiretroviral medications have in facilitating optimal health outcomes for PLWH, the pharmacy and the pharmacist are thus integral places and people pertinent to their care.

The following quote showed that there was a fear of the pharmacy, a fear of inadvertent disclosure of a person's HIV status within their suburban community. "Also, there was this question of let's say you have to pick up medication and the kind of medication that you would have to get from the local pharmacies within the neighbourhood. So I had concerns about that." The fear of the pharmacy was interpreted

as a fear of seeking health care because antiretroviral medications are foundational to favourable outcomes for PLWH. All of these lived experiences demonstrated how pharmacies can unintentionally and publicly disclose a person's HIV status, and thus were an environment that had the potential to generate fear of community-level stigmatization.

4.2.5 Stigmatization by Health Care Practitioners and Within Health Care Settings

Dentist offices, which are privately funded and delivered health care services, were a location where co-participants experienced denial of care, breaches of confidentiality related to living with HIV, and stigmatization:

So, in particular, HIV, I haven't had a 'no' because of HIV. I have heard 'no' saying that my dental benefit is ODSP. I don't know why. And sometimes that dialogue has been: 'Well, ODSP is only going to cover one visit per year, and for you to enroll as a new patient, we're going to need to see you at least twice: the initial visit is an assessment, the second one practical services. And one of those is not going to be covered and it's going to be this much money.' So it's not even so much that they're saying 'no' in that circumstance, but just that the money is prohibitive. The expense is prohibitive.

Yes, at my dentist's office. I was bringing one of my forms for her to sign because it was easier for me to get the signatures then to confirm that I actually went to the appointment rather than to wait for the audits. And this girl just sat there and started flipping through – this is one of my heavy months when I have like 24 pages of documents and she started skimming through them. I said: 'Excuse me, what are you doing?' She said: 'Nothing, I'm just looking at what I'm to be signing.' I said: 'I've told you what and where you're to be signing. You have no right to be perusing through the rest of those pages – that's my private information. All I've asked you to do was to sign to verify that I was here on your space right there that I just pointed out to you.' She said: 'Yeah, yeah, yeah, ok,' and she kept flipping through the pages. I said: 'May I have my documents back?' It didn't go over well. She was looking at information from the naturopathic clinic at 333 Sherbourne Street where it said I'm HIV positive.

One of my teeth started to hurt. I don't know if it was because I had never experienced the cold or what it was. And I didn't know any other dentist I only knew of it because it was where I processed my refugee medical assessment. So I decided that I was going to go as a walk-in and I told them that I didn't have an appointment, but this was what was happening. I told them up front that I was poz

[seropositive]. The reaction, if looks could kill, they were so scared of me. He put me in a chair and looked and didn't do anything. And then he goes: 'Oh, we wouldn't be able to do anything at this time. We're full, but I could write you a prescription or maybe recommend another dentist.' I was like: 'Ok.' He was so scared of me.

One co-participant said: "I would loosely say yes that there was a stigma, more so I felt it was clinical, that they use medical speak to sort of create a separation. And just for clarification, it hasn't just been doctors." This statement showed how some health care practitioners utilized their clinical expertise and knowledge to manipulate the dialogue for the purpose of stigmatization. Other co-participants spoke about stigmatizing experiences within hospitals and community or walk-in clinics in their suburban community:

Well, one doctor up there at the hospital, remember I told you? And I was in a lot of pain. I broke something, and he refused to give me anything because being HIV positive is written right on the front page. And he figured, I mean, he's a doctor, he should know better. He just figured that because I had that, that I've been a junkie. I was angry and I broke down and told him how I got it. I said: 'You're a doctor, you should know better!'

So, it's strange that I, like I told you, I wasn't on meds first, and I got really sick, and I was at the emerg like three or four times in one month. The thing is, when you go to emerg, there's a sitting room there and the office there. And you go in and tell the nurse if you've ever been there, what's your ailments, stuff like that. And I went in there and I was sitting there and there's the sitting room right opposite. And she was asking me if I have a fever and if there's anything else, and I said: 'Oh yeah, I'm HIV positive.' And she said: 'HIV?' like shouting it out. I was so embarrassed. So stuff like that, you always have to look, and it made people scared because the reaction that you get sometimes from medical professionals – shouldn't you know more about this than I do? It's 2016! Do you have to be that scared of somebody or be so closedminded? Like, come on! This is not the 80s were everyone was so scared and we didn't know what exactly it was. You know it's 2016 and these are people who are trained medically, and you've got to leave it to people who don't know anything in my country that have this fear, you know? And you're thinking that the medical thing, it would be different, but some of them are more scared of you than anything.

One of my best friends, who has passed away now, he was sitting in the doctor's office waiting area and the doctor walked out and said: '[Friend's name], you

have AIDS,’ and turned around and walked out. And he was left there crying. And I’m going: ‘Are you kidding me? How insensitive?’

So I went in, and the nurse that was there, she kind of looked at me, she looked back at my papers and she saw that I had HIV and made this really gross face. She started reading my information out loud in front of other people. That really struck me and really upset me because we live in a world that has stigma and discriminates against people living with HIV. People look down on you and act like if they touch you or hug you that they’re going to catch it, but that’s not how it works.

In these instances, it was evident how the negative assumptions, beliefs, and biases that were possessed by health care practitioners about HIV were projected on to PLWH. These stigmatizing experiences within suburban health care settings underscored the challenges that PLWH encountered in seeking and accessing health care within their suburban community.

4.3 Personal and Unintentional Biases About HIV

Two groups of people were captured under this theme: health care practitioners and people within the community. Findings from both of these groups emphasized the implications of these biases. Specifically, the effects that the biases had on the ability of co-participants to feel comfortable within health care settings and to develop healthy relationships with others in their community.

4.3.1 Personal and Unintentional Biases About HIV Among Health Care Practitioners

Multiple co-participants identified instances where the behaviours of health care practitioners illustrated personal and unintentional biases about HIV and its transmissibility:

It used to really, really, really bother me when I would disclose at the hospital, if I was in for whatever reason – an emergency stop or something scheduled. When

the people would actively – you're not supposed to actively cap a needle. It used to really bother me when they would do stuff like that. It would really affect me.

These unintentional biases about HIV contributed to the performance of unsafe handling of sharps, such as needles and syringes, which had the potential to transmit HIV and other blood borne pathogens. These behaviours placed patients and providers at risk and should signal to those involved with patient safety and quality improvement initiatives to provide further education on HIV to front-line staff. In the next quote, the personal and unintentional biases of some health care practitioners about HIV contributed to the co-participant feeling shamed and having a negative experience accessing health care services:

There's still a lot of work to be done with people here. They need to be well-educated: you're not going to catch HIV by touching the person, hugging the person, shaking their hand or hanging out with the person. You and I know very well how you'll catch HIV, how it's transmitted. So it's hard, and that's why I don't access anything up here. It's why I go all the way downtown Toronto. Downtown Toronto, I've never had a bad experience.

It was evident how the personal and unintentional biases that a health care practitioner may possess about HIV, and about the health needs and demands of PLWH, directly influenced how PLWH perceived the quality of their health care.

4.3.2 Personal and Unintentional Biases About HIV Among People Within the Community

A co-participant discussed the perceptions and assumptions of HIV that are possessed by her classmates at a local postsecondary institution and how personal and unintentional biases perpetuated community-level HIV stigma:

I would like to volunteer whenever I have time, now I can't because I don't want the association. I guess the bottom line of what I'm trying to say is the stigma is still there, and, for instance, when I'm in the college, with the course that I do, discussions come up and you hear the comments that people make about HIV and

AIDS and how nasty it is and all sorts of things that they say, how they would not want to be around a person who is – I’m sitting right there and I’m listening and I realized that no matter how long this has been around, people are still quite ignorant and afraid of this disease. And you can’t begin to imagine.

One co-participant explained how, in his experience, there is an absence of education to reduce harm from sexual activity:

Going online and talking to guys, especially myself being poz [seropositive], and people that have in their profile that they’re into, say, barebacking, unsafe sex, and then they find out you’re poz [seropositive], and they drop you like a hot potato because they’re in a bi relationship. And for me, it doesn’t make any sense that you’d put your partner at risk and if you knew the consequences of what your ass is out. There is no cure for HIV and some people think there is.

This quote showed how the personal biases about HIV and safe sexual health practices had negative consequences for PLWH who are forthcoming about their seropositivity and how it contributed to feelings of isolation. Both of these examples illustrated that there was a need for better public health messaging about HIV to mitigate community-level stigma within the suburban community.

4.4 Isolation

Isolation came in different forms: isolating self, and isolation attributed to a lack of community. Broadly, isolation was expressed by co-participants with statements such as: “We’re not close friends with anyone; I don’t think there’s a lot of social support... I feel lonely living out here... I feel isolated everywhere we’ve lived.”

4.4.1 Isolating Self

One male co-participant expressed how his identity as a heterosexual, cisgender male makes him feel as though he could not participate in supportive HIV programs because they were targeted at men living with HIV who also had sex with other men:

There’s a support group and it takes different forms. Sometimes their outings are just social. Other times, it’s an instructional video and having some dialogue

about it. I don't feel I can participate in that group because I, I guess I feel that because I'm married I'm defined as a straight person and wouldn't be welcomed in the group.

Another female co-participant stated:

I would say especially when I first came, everything felt so isolating. And it still happens sometimes. Sometimes you just don't feel – you feel like there should be more. Like you should be doing more. Like there should be, I don't know, like getting out with more positive more, just more. You want to do more. And sometimes you don't know what to do. Especially in the winters up here, I do start to feel isolated and all closed-in and boxed-in.

These examples illustrated how PLWH in the suburban community felt as though they were stuck and segregated from their larger community. It also underscored the importance of creating inclusive, accessible community groups to mitigate feelings of isolation.

4.4.2 Isolation Attributed to a Lack of Community

One co-participant said: “Even the straight women counsellors at ACDR keep saying that: We have so many men who are gay who are regularly expressing how there's so many other gay men in the Durham area who are lonely, isolated, unhappy.” The lack of community was also attributed to a lack of perceived diversity in the demographics within the community, which would have implications for many other groups or people who may feel like they are the only one like them in their suburban community (e.g., people with developmental disabilities, etc.). This lack of a sense of community was also found in many other co-participant experiences:

I used to come to – they used to have a regular support group. But we, the long-term survivors, you'd think we'd be mentors to – and we've all taken courses to mentor those who are younger coming in newly diagnosed with HIV, but they don't want to be around us. They don't want to end up like us, it's most peculiar. They don't really even want to be identified, and they don't want to share in a support group. When I initially came to my AIDS service organization, there was

a great support for each other: we cooked together, we did projects together, we expressed ourselves together.

There's times when I want to get together with people and be able to be HIV positive. I don't use the label openly. If people have asked, or if they are curious as to different things that I may have let slip, I'm not secretive about it in that sense, nor do I advertise. But there's times when I would like to be with a group of people where I can wear that aspect openly, and certainly you can't – I can't find an outlet for that in Durham region.

It's not that I had them. I, you know what, just as I was answering that question now, they were my relationships. Wow. I've – they were my social life. Sitting here now, outside of a service provider, there may be one or two people I could call and say: 'Hey, do you want to go for coffee?'

I feel a bit alone. I feel a bit like you're thrown, you know, like an animal you don't want and leave him in the backyard and just let him stay there. That's the way I feel, to be honest with you.

These quotes validated how PLWH in the suburban community were isolated, largely because of the absence of a supportive, inclusive community. These findings further substantiated the need to develop community groups.

4.5 Transportation, Cost, and Time: Barriers to Access

Co-participants identified how transportation, the associated costs of transportation, and the time required to travel to care were significant barriers to accessing care within the suburban community, especially if PLWH relied on public transit and/or taxi services:

Particularly when I was existing exclusively on ODSP support, yeah. I mean it's a very modest income to begin with. So a \$60 taxi is not in the budget at all... Unfortunately, the sacrifice is generally your health. You don't spend the \$60 on a taxi, you don't go to the appointment, you just sort of hope the issue will resolve on its own and not develop into something more serious.

Regarding transit, it is such a huge investment of time trying to travel by transit. If I were driving, I could spend 10-15-minutes travel time. Travelling by transit however, that time swells to an hour or more. If you're considering urgent, or walk-in services, transit is simply too prohibitive, it's sadly easier to shut oneself in, to not travel.

Other co-participants spoke about their discontent with the efficiency of the suburban public transit system: “Oh God! If I didn’t have my car, I wouldn’t go to the half of them. It’s too much work. Public transit? I couldn’t get there and back if I didn’t have a car.” “TTC stands for Take The Car. I’m just not doing it.” Others also identified how long and arduous their commute by public transit was to attend medical appointments:

Transportation is the hardest part here. With just being new to the city, it’s getting used to the bus systems and getting there... A bus doesn’t run from here to my doctor’s in a straight line: I’d have to go downtown and then back uptown. It doesn’t make sense.

Here’s how hard it is for me: I have to take the 407 bus and go to Oshawa, then wait for the 90 to get to the GO station. And then sometimes I would get there and see the train taking off, or sometimes I would be on the bus praying – please, please, please – because I’ve still got to go and buy my ticket. And it’s so stressful going through all that. And then when I get on the GO Train and get off and go to the TTC and have to take the streetcar, it’s just too much.

Sometimes it could be a bit much, you know? Just trying to get to where you’ve got to go, especially transportation-wise. Because Oshawa is not like Toronto – it’s not every 15 minutes. And sometimes it’s a pain and I get so weak. The last time, I had to call my sister from work. I was going to see a gynecologist because I was menstruating for five months straight and my blood count was so low. I always have a low blood count in any case, but I was so weak I tell you, I couldn’t even stand up for very long. And I just couldn’t put on my clothes and go there and stand and wait for the bus... So sometimes it’s hard getting to the appointments, especially when you’re not driving.

So for me, it’s a little bit hard traveling over there, the wait times, the travel times and the traffic, and then waiting to come back home. Why do I need to go all the way down there? Why can’t there be a better, easier way for me to access a doctor that is a specialist up here? That I haven’t been able to find up here.

Another co-participant said how delays in public transit resulted in her missing her original appointment time and how she was unable to access the care she needed:

One time, I was late. I was given another date, two weeks ahead. I was feeling so bad and I told her I was late because of the bus, but she said there is no other option, and she pushed me away to come home and to wait for the date that they updated.

Other co-participants discussed the competing priorities between transportation, food, and healthy eating: “I spent \$8,600 in six months driving back and forth to Toronto... There’s times when I’ve had to do without food in order to put gas in the car.” Another co-participant said:

It’s a fine line between food and transportation. Budgeting food costs and travel has been hard, especially when I first moved here. We were behind the ball for about the first three months, trying to get money back rolling again in our favour. We would have to walk down to – we didn’t even know about the ACDR at that time. We would have to walk down to the food bank, grab our food and then walk back, which is not fun going through uptown and downtown. And that happened a few times trying to get food.

The ACDR provided a volunteer driver service to clients to help them attend their medical appointments. However, the scheduling of the service was a barrier to care, especially if the need for the service was immediate or an urgent situation:

Yeah. I shattered a couple of knuckles. A lot of pain. My hand was huge, and I didn’t have any money. I called the ACDR and they told me that they needed two weeks. I said: ‘Look, this just happened and I need to go get this checked.’ ‘We can’t help you.’ So I had to wait. I had to wait until my work disability came in before I could go.

You have access to volunteer driver programs, but they like to schedule that in advance. And as you sort of interpreted, my routine HIV appointments were easy to schedule a volunteer driver for, but when going in for a more urgent or immediate health concern... that’s not always falling into a timeframe where the volunteer drivers can be scheduled.

I have to call the ACDR and we only have one driver for years, now we have three. But we have to give them two weeks’ notice. So, say my cardiologist or my gastroenterologist needs to see me right away, if it’s not two weeks, they wouldn’t even put our name on the list unless we give them two weeks’ notice, which is bull.

Transportation is thus an important consideration for PLWH in suburban communities. The experience of many PLWH authenticated how the rudimentary public transit systems in suburban communities made it challenging to be mobile and attend

medical appointments or seek care or supportive services. These experiences additionally illustrated the importance of accessible, community-based care for PLWH and people living with multiple, chronic health conditions.

4.6 Flawed Delivery of Health Care Services

The theme of health care service delivery captured how PLWH experienced deficiencies in primary care settings or had their needs deflected to their specialist; how health care practitioners shared information about their PLWH patients, but did not collaborate to create care plans; explicated how many health care practitioners additionally work within silos; and illustrated how PLWH have multiple, chronic health conditions that would have greatly benefited from increased interprofessional community-based care initiatives.

4.6.1 Deficiencies and Deflected Needs in Primary Care Settings

One co-participant identified his unease accessing care in a suburban community: “You’re always thinking: ‘What’s next? What idiot doctor am I going to get?’” Some PLWH said how their health needs and concerns in primary care settings were unmet or deflected to their medical specialist or another specialized health care practitioner:

My family doctor openly admits that he knows nothing about it, and any time I come with an issue, a physical issue, he’ll send me to a specialist, specializing, say in that part of my body or that particular situation.

Yeah, you have to know what HIV drugs you’re on and what can affect their effectiveness by taking anything else... And as they say: ‘It’s your responsibility,’ and that’s a real effort to maintain, especially now that I’m 26 years with this.

Accessing health care that, my personal interpretation, is not related to HIV is often challenging in the sense that when you see a family health practitioner, and you disclose your HIV status, they automatically assume that whatever health concern you’re presenting is HIV-related and so direct you to go to the HIV care clinic as opposed to addressing flu symptoms or whatever else it is that you’re going in for: you know, migraines in one case, or digestive problems, or

swallowing problems that I've experienced, which, speaking to my HIV peer network, doesn't seem to be related to my HIV status, but approaching family physicians, or urgent care clinicians...

So in the interim, I was enrolled in a nurse practitioner program. Specifically, through a peripheral health concern of mental health, suffering with depression, that sort of gave me an entrance into what became a substitute for a family medical care. But again, most things that I presented in those appointments were largely ignored or it was suggested that I review those with my HIV specialist.

If you have to walk into any urgent care, most of them don't even know what is going on with the medications for HIV – I know more than them – so it's hard having a family doctor that knows nothing. And then you have to explain everything to him. It's hard getting somebody who doesn't know anything.

But, how I feel when I know he doesn't know a whole lot about it, not confident. It makes me worried. And the first time it happened, it was so surprising that a lot of them, they don't know a whole lot.

The regular deferral of chief complaints in primary care settings to medical specialists or advanced practitioners validated the inequity in care – and access to the appropriate care at the appropriate time – that PLWH in a suburban community experience.

4.6.2 Sharing Health Information Versus Collaborating on Care Plans

It was evident in experiences expressed by co-participants that within the course of their care, their health care practitioners were sharing pertinent health information about them with others involved in their care, but were not collaborating with those professionals and building upon their expertise to create a care plan. One co-participant said: "I guess most of the time it's going over history that you repeat a lot." Another one said: "Sometimes I'll be given a pill, but I shouldn't be taking it because I'm taking another pill and it'll take away the strength of that pill – and that's happened." Other co-participants said:

Yes, the Positive Care Clinic and my family physician are consistently sending stuff back and forth. If my doctor wants me on something, he'll send a note to my psychiatrist, for example, for my depression pills and so on.

I went to my [general practitioner], he sent me to Lakeridge. Lakeridge kicked me back to the Positive Care Clinic, the Positive Care Clinic back to my [general practitioner], and this went on and on and on. It's still going on!

These quotes illustrated how the lack of true interprofessional collaboration resulted in disorganized care, but also led to medication errors that could have had grave consequences.

4.6.3 Care Delivery in Silos

Building upon the theme of sharing information but not collaborating, the experience of PLWH in suburban communities illustrated that health care practitioners appeared to be delivering care in silos:

He wouldn't give my flu shot – this latest pharmacist, because he was worried that nobody was monitoring my conditions after he would have administered this flu shot... Every time I go, they want to go through my list with me to confirm this is what you need, this is what you're taking, is this current, have you had a – are you maintaining a regular schedule with your family doctor and your specialist, are you getting your blood work done, are you maintaining this healthy liaison with the health services...

Another co-participant expressed a similar experience: “Dr. [name withheld] wrote the script, and I said: ‘Where do I get this done?’ and she told me: ‘Go see your [general practitioner].’ She wouldn't even look it up, it was pathetic.” The finding of health care practitioners working in silos further compounded disorganized care and affirmed health inequities in health care service delivery for PLWH in the suburban community.

4.6.4 Ageing with HIV: The Need for Community-Based Interprofessional Care

Almost all of the co-participants interviewed articulated that HIV was not the only chronic health condition that they were concurrently managing. One co-participant said: “I have all kinds of health problems... Yes, it's my third [cancer].” Others discussed ageing, life with HIV, and the effects on other body systems: “Yeah, in your older age,

having served a long time living with HIV, HIV doesn't become the primary health issue, it's other things that begin to crop up and I developed problems with my joints." "I have a lot of other issues besides HIV because of HIV. It's the first time I've been told my kidneys shut down or renal failure is caused by HIV." "I'm on disability. I've lived in chronic pain for eight, nine years." Others discussed mental health and addictions: "Living with schizophrenia... Well, in my life, like I said I'm a recovering drug addict." "My anxiety and depression also developed from the diagnosis in 2008. And I have cancer also too. So I was diagnosed with both in the same year at the same time." Others also discussed the challenges they experience as a result of multimorbidity:

This, around here, is called lipodystrophy, which is a relocation of the fats of your body and a humpback and, you know, around here it accumulates, and the joints became a factor because that's like, arthritis, and I'm pretty sure they've diagnosed me with osteoarthritis. And I have trouble moving now with my lower back, walking great distances or standing for a long time. And I've also developed diabetes, type 2.

I suffer from chronic back pain, degenerative disk, osteoporosis, 70 per cent. Osteoporosis throughout the body. So, I'm a 55-year old man but I'm in a 78-year old's body. Very brittle, so I've got to be very careful, things like that. I suffer from depression. Optician for my eyes, a urologist – I have urinary problems.

I've had three strokes. I have stomach problems – I have all kinds of problems. I have degenerative bone disease and I have osteoporosis really bad. I've got Crohn's. I have a-fib. I have a stent in, and they're talking about now giving me a pacemaker. I'm falling apart. I had cancer.

Deal with it. Nothing. That's why I'm happy to be getting a psychiatrist because I need someone to talk to about, you know? I have a dermatologist and an endocrinologist and another one that I can't remember. I have different ones for different stuff because different things come up.

Another co-participant expressed how his medication regimen caused him to be unable to drive: "I used to drive, but I'm not allowed to drive anymore because of the medication that I'm on, right? It makes me drowsy and dizzy, so I could put my life in danger and put

others in danger.” As transportation was an issue identified by many PLWH, coupled with the finding that many are concurrently managing multiple, chronic health conditions, it further emphasized the need for interprofessional and community-based care to be accessible within suburban communities. Moreover, these findings pointed to the fact that further consideration for the relationship between healthy aging and access to interprofessional, community-based care needs further consideration by policymakers and community-based service organizations.

4.7 Inefficient, Antiquated Social Care Service Delivery

The theme of inefficient, antiquated social care service delivery consisted of experiences where co-participants reported poorly coordinated and restrictive social care services from the government that influence and affect their access to health care services. Co-participants also reported how the social care services were disconnected from the health care services and how the disconnectedness was a factor in how they ranked their care.

4.7.1 Poorly Coordinated and Restrictive Social Care Services

Many co-participants identified numerous issues regarding the social care supports and how they are provided. One co-participant discussed a lack of resources and challenges navigating the social supports:

When I look at my own personal journey, a lot of the resources that I made use of or was made aware of, don't exist in Durham region. So I can't imagine what the experience for people who are diagnosed in Durham region must be like. It would be like being in a bumper car and your vehicle doesn't drive: you're just being hit by everything and thrown all over the place.

It was the social services that were really, really difficult to navigate, and they're an ongoing challenge here. I moved three months ago. When I call them, they won't acknowledge that they've received my change of address form, and yet they send my ODSP statements and my dental and health benefit card to my old

address, but they've determined that I owe them money because they've overpaid, but they manage to send that to the right address. And they still don't acknowledge that they haven't received my change of address, right? So, it's a frustrating system. Social supports: huge, huge problem.

Other co-participants expressed how the services are restrictive, do not offer the support they need, or challenges accessing the social support workers:

They're designed to say no. See, the Act is the legislative body, whereas the people that are running it, most of which are, to-date, caseworkers instead of social workers and midlevel bureaucrats that are operating under management pieces that are structured like an insurance company, for example. We have this policy and this is what we're offering, but when you come looking for it, we say no. We're going to make you work to get it. And we're not just going to make you work, we're going to make you WORK! Instead of one hoop, there's 20. And we will not cut off three at a time, we'll cut off one, one, one. And I learned that the hard way in the first couple of appeals I made. So now when I go at it, I'm covered for six, seven, eight hoops in one shot, in one letter. I know the key phrases and words to put in and I communicate with my specialist and they put them in for me.

They'll say they won't do it based on a referral; they have to know that it's been prescribed. So then I have to get a prescription, and then they'll say that they need to know if it's necessary. And then they'll come back saying that it's prescribed and necessary, but is it essential? And then you'll come back showing that it's essential and they'll say: 'No, is it essential based on the fact that you're HIV positive?' And most people, by the time they get to the third letter, just give up and walk away.

But the thing is, I find it really restrictive and it's hard sometimes trying to access the simplest of things – and they're the things that you would think they would care more about – no! They're cut. I was going through – I'm still going through – my immigration stuff, and they don't help with any of that. Anything that you have to pay for, although you're on ODSP, there's no one to help you. You have to come up with the money to pay for it. There's no help with that. Every time you call: 'Oh no, we don't do that. No, we don't pay for that.' There's a whole lot of stuff that you would think, you know, I mean, I'm on a fixed income and it's hard trying to find \$600 to pay for this and that when my income alone is \$1,200.

No, it's just a worker that I'm assigned to at disability. So if I need anything, or if anything has changed, or if I'm looking for work, I have to call her. Sometimes, it's hard to access her because sometimes she's really hard to get a hold of. So you feel like, how do you go about doing the things you want to do? How do you go about getting the services that you need, if you don't have that great support

from the workers? Like, those workers are supposed to be there working for you and helping you the best way they can. So sometimes it's frustrating.

These quotes authenticated that the social care systems and delivery frameworks currently in place need review to better support PLWH and people in a suburban community with multiple, chronic health conditions.

4.7.2 Disconnect Between Social Care and Health Care Service Delivery

A co-participant clearly articulated how the support and assistance he was supposed to receive to transport him to and from his medical appointments was a challenge to coordinate with the government:

It's a taxi company that I have to look for by myself, which is another thing that I found to be a little bit hard when I first came to this area. The worker told me that I had to look for a company. I used to live in Mississauga and they used to do everything; disability knew which cab company they were going to work with. But here, I had to look for the cab company and I had to keep calling and calling, and then call her and tell her the name of the cab company. And then she would tell me that they don't work with that cab company or this cab company. And I'm like what do I do? Who do I call? Finally I got fed up, but she – I found a cab company that would take me.

This quote showed his dependence upon transportation for access to care. The relationship between transportation and access to care was overseen by social support workers within the provincial government, but little consideration was given to how the social support connected to health care service access and delivery.

Chapter 5: Discussion and Conclusions

In this chapter, I present the significance of the results, interpret them, and provide directions for future research. This research aimed to investigate the following research questions: (1) How do suburban PLWH access health and social care services; and (2) How does the structure, design, and population demographics of the suburban community influence and affect the access of PLWH to health and social care services? There are three areas of discussion: (1) Stigmatizing experiences and education about HIV; (2) Transportation and access to services in suburban communities; and (3) Cohesive health and social care delivery. These areas have implication for the education of health and social care professionals, health and social care policy, the delivery of health and social care services within communities, and ageing within communities. Lastly, I conclude with a summary of the research and opportunities for further inquiry.

5.1 Stigmatizing Experiences and Education About HIV

In the following section I discuss the interconnectivity between HIV stigmatization, gender, within communities, and within health care settings. I also discuss outreach within social media, as many people, including PLWH, use the internet to connect with others and formulate communities.

5.1.1 HIV Stigmatization and Gender

There were differences between genders regarding HIV stigmatization. For example, men reported stigmas that intersected with their sexual orientation or other health issues, such as addiction. In contrast, many women PLWH in this inquiry immigrated to Canada from a country where HIV is endemic and expressed experiences

of generalized stigma and concerns regarding confidentiality of their personal health information.

5.1.2 HIV Stigmatization Within Communities

HIV stigmatization occurred within multiple communities. Co-participants who identify as part of the LGBT community explicated how they experience HIV stigma from other LGBT persons. The stigma expressed by LGBT non-PLWH took the form of avoidance of being in any space that had connotations of HIV. Holtzman et al. (2016) described how the size of a community's population could influence the extent to which PLWH experience discrimination and have reduced access to care. Boulden (2001) found in his interviews with gay men in Wyoming that they were hypervigilant to being aware of how they were perceived within their community. This hypervigilance was also noted in this inquiry; although the hypervigilance is interpreted through the statements of PLWH, it is a behaviour of non-PLWH. As Holtzman et al. and Boulder performed their research within a rural environment, this inquiry within the suburban environment has hues of the findings from rural communities and how LGBT and PLWH experience their lives within those communities.

HIV stigmatization also occurred within online communities. The use of internet to connect with other gay men is noted in the literature (Hubach et al., 2015; Schnarrs et al., 2010). In this inquiry, it was reported by co-participants that when they would disclose their HIV status, they would no longer receive responses from the person or people with whom they were previously communicating. As online communities and the use of social media platforms continue to be integrated into modern living, reducing stigma for PLWH within these mediums is important to create feelings of inclusion.

HIV discrimination and stigmatization within a local postsecondary institution highlights the fact many youth and young adults do not possess up-to-date information about HIV, its transmissibility, and the challenges with which PLWH endure in their lives. This finding has implications for policies regarding inclusion and harassment within postsecondary institutions because the inappropriate comments made by students in classrooms and on campus can, and in this inquiry did, have a negative effect on co-participants feeling included within the campus. Instructors and administrators should strive to provide the necessary education and link students to resources on campus.

5.1.3 HIV Stigmatization Within Health Care Settings

There is substantial literature, across many countries, that details the stigma PLWH face in clinical health care settings (e.g., hospital, medical clinic, etc.) and health care settings within the community (e.g., pharmacies, dental offices, etc.). One finding from this inquiry that requires further discussion is how PLWH encountered challenges in accessing oral care from dentists. Dentist services (e.g., fillings, cleanings, etc.) are not covered in Ontario under the public health insurance plan, OHIP; only services rendered by a dentist in a hospital are covered (Government of Ontario, 2016). It is concerning that PLWH experienced stigma (e.g., fear of physical touch, referral to other dentists, inappropriate facial expressions, etc.), and were informed that their provincial support benefit, ODSP, was prohibitive for accessing the care they would need from that dentist's practice. Edwards, Palmer, Osbourne, and Scambler (2013) also found in their interviews with PLWH that stigma within dental practices exist and are a barrier to care. Considering the importance that oral care has in regards to the maintenance of good

health and wellness, further education regarding the needs of PLWH should be provided to dentists and oral health care professionals.

Pharmacies were another notable example of a health care setting where PLWH endured stigma. Studies conducted by Haack (2008) and Rickles, Furtek, Malladi, Ng, and Zhou (2016) identified that pharmacy students need more exposure to diverse populations. Moreover, Rickles et al. determined in their study that some pharmacy students have adverse attitudes to being physically close to PLWH. This finding in their research corroborates the experiences of PLWH in this inquiry. Therefore, further education about HIV, including how HIV is transmitted, should be provided to these important health care professionals to mitigate and eliminate false and inaccurate perceptions of PLWH.

5.1.4 Education About the Needs of PLWH

PLWH in this inquiry commented that health care practitioners were not as knowledgeable about their needs as much as they would like them to be. Their concerns encompassed knowledge regarding currency of HIV antiretroviral regimens, social care needs of PLWH, and mental health. These findings iterate the importance of health care practitioners being equally engaged in the care guidelines and recommendations that a patient, or PLWH, requires.

5.1.5 Outreach Via Social Media to Increase Education About HIV and Mitigate Stigma

Co-participants identified that trying to meet other people online, especially through mobile dating applications, was challenging. Many non-PLWH who also used those platforms lacked education about HIV, and this led to feelings of isolation and

segregation in PLWH. Herein lies an opportunity for public health departments, health promoters and educators, and people involved in harm reduction to perform outreach to increase education and reduce the propagation of false information about HIV and its transmissibility. A recent case study conducted by Lampkin et al. (2016) in suburban communities illustrated that having health promoters engage with users of mobile dating platforms, such as *Grindr*, resulted in a substantial outreach and sustained engagement with those users to seek STI and HIV services. These results show promise of efficacy and innovation in the changing landscape of how to connect with high risk groups as they migrate to online environments.

Also, as it was identified that some co-participants experienced stigma within their postsecondary educational institution, outreach via social media also could have promise for mitigating HIV stigma. For instance, many reports show that students who are entering postsecondary education have grown up with social media and are highly connected online. As the results from Lampkin et al. (2016) showed success in outreach and engagement with users within a social media platform, it is plausible that similar results could be achieved with social media campaigns to reduce stigma associated with living with HIV. Additionally, online outreach could connect users with services and be a highly valuable tool for assessing community-level health needs and using this data to craft or revise policies to reflect the needs of the community.

5.2 Transportation, Access to Services, and Community Development

Transportation to care was a barrier to accessing services for many co-participants in this study. As some co-participants did not drive or have access to a vehicle, effective and efficient public transportation systems were essential components of their ability to

access health and social care services. Furthermore, transportation was identified as a contributor to feelings of isolation and disconnectedness from others. In the following section, I discuss the implications of transportation barriers on access to services and the role of community-based organizations and community development.

5.2.1 Transportation Barriers

Many co-participants identified how traveling by public transit was arduous and a challenge in accessing care. This finding confirms the notion expressed by Paez et al. (2010) that a person's ability to travel and access health and social care services is a better indicator of their access, rather than measuring the distance a person must travel and the time they must spend to access care. As there were fewer than expected co-participants who travelled to Toronto to access services for the management of HIV, the experiences of these co-participants explicate that they travel to preserve their anonymity and maintain continuity with their health care providers, which also is consistent with some of the literature (e.g., Carman et al., 2010; Eberhart et al., 2015; Mugavero et al., 2011). Some of these co-participants identified that they traveled to Toronto because they endured stigmatization for living with HIV when they accessed care in their suburban community. These findings add to the body of literature that already documents the challenges PLWH experience with transportation, perceived or actual stigmatization within their community, and access to care (see Carman et al., 2010; Cunningham et al., 1999; Eberhart et al., 2015; Heckman et al., 1998; Kemp et al., 2010; Reif et al., 2006).

To mitigate the challenges associated with transportation and access to health care services within suburban communities, health and social care system leaders should have on-going dialogue with urban planners, geographers, and transit planners. It is important

to consider how people utilize public transit, or any mode of transportation, to access health and social care services because it would have an impact on their engagement and retention in care. The findings in this inquiry illustrate that unmet health needs within suburban communities, where public transit systems may not be as comprehensive and in operation at almost all hours of the day as in urban centres, such as Toronto, are greater. Research on suburban poverty and health service access identified transportation first and foremost as a barrier (Felland, Lauer, & Cunningham, 2009). In addition, this finding adds to literature describing the relationship between modes of transportation and access to care for PLWH from the United States (e.g., Dasgupta, Kramer, Rosenberg, Sanchez, & Sullivan, 2016; Sagrestano, Clay, Finerman, Gooch, & Rapino, 2014).

The cost of transportation was another barrier expressed by some co-participants, and some also spoke of how they had competing priorities between their transportation needs to access health care services and their ability to secure food, which is an important social determinant of health (Mikkonen & Raphael, 2010; Raphael, 2010). Mackett and Thoreau (2015) also discuss how the cost, and rising costs, of transportation is a significant barrier for vulnerable populations, which would include PLWH. As suburban communities are susceptible to sprawl (see Forsyth, 2012; Frumpkin, 2002; Hancock, 2000), the distances that need to be traveled to access services are greater and require more time dedicated to traverse them. Thus, a positive correlation between the cost of transportation and distance traveled would exist, especially in cases where public transit is unavailable or out of service and the use of a taxi is the only available mode. The barriers PLWH in this inquiry experienced regarding costs of transportation and the time spent traveling to care reiterate the need for accessible, community-based services.

With the increasing population growth and diversity of residents within suburban communities, there are likely to be diverse health and social care needs and diverse needs for transportation to access care. A recent qualitative study conducted in Texas on transportation mobility within a low population density city – mirroring physical attributes of a suburban community – revealed that people who experience inequity in their ability to travel to care have reduced access to health care, social services, and are far more isolated (Adorno, Fields, Cronley, Parekh, & Magruder, 2016). The results from this inquiry support their findings and demonstrate how local policies pertaining to the delivery of health and social care services should be examined to achieve greater equity for vulnerable and stigmatized populations, such as PLWH.

Co-participants did not discuss how the design of their suburban community influenced and affected their access to services, and many co-participants stated that it was not something they thought about. While co-participants discussed the multitude of transportation barriers and how they wished there was more available transportation within their suburban community, they did not acknowledge how the design of the community determines the comprehensiveness of the public transit system. Herein lies an important consideration for policymakers regarding how land use, development, and health care access are interconnected.

5.2.2 The Role of Community-Based Organizations and Community Development

This inquiry determined that PLWH in suburban communities experience isolation and segregation, largely due to the finding that they lack feeling as though they are a part of an inclusive, supportive community of people with shared interests and life experiences. Studies regarding social exclusion and transportation conducted in the

United Kingdom (e.g., Boniface et al., 2015; Mackett & Thoreau, 2015) establish the importance of community connectedness and how they influence health outcomes. When examining how co-participants described their feelings of isolation, it is evident that there is work to be done within communities to bring people together.

The feelings of isolation and segregation may be attributed to the fact that urban centres or cores have distinct neighbourhoods and communities where people with similar life experiences congregate, whereas suburban communities typically do not have these distinct, cultural areas. Research conducted by Reynolds, Mackenzie, Medved, and Roger (2015) supports the notion that supportive and connected community groups help to alleviate feelings of isolation and depression. Their findings provide community-based organizations and groups sound advice for engaging participants: flexibility in the programming and emphasize the participation and engagement of the group of interest at all levels of conception, implementation, and review (Reynolds et al., 2015).

Additionally, a recent cross-sectional study (Webel, Sattar, Schreiner, & Phillips, 2016) identified that social belonging for PLWH is associated with favourable health outcomes, which further emphasizes the need for the development of inclusive, supportive communities. Community-based organizations and groups that service PLWH, such as the ACDR, should perform additional outreach and engage with members to establish additional mechanisms that could help bring PLWH in suburban communities together on a regular basis. This could facilitate the development of supportive, inclusive groups to mitigate feelings of isolation and segregation that were communicated by co-participants in this inquiry.

5.3 Cohesive Health and Social Care Service Delivery

Cohesive health and social care service delivery requires discussion. Co-participants identified significant overlap between their health care service access needs and the social support services and mechanisms that enabled their access within their suburban community. In addition, this inquiry revealed aspects of how the delivery of primary care services could be improved, such as the reduction of unmet or deflected health needs in primary care; greater integration of pharmacists and the pharmacy into primary care; the need for interprofessional, collaborative care for people living with multiple, chronic health conditions and healthy ageing within communities; and amalgamation of health and social care services.

5.3.1 Reducing Unmet and Deflected Health Needs in Primary Care

Co-participants in this inquiry identified how their health concerns they addressed in primary care settings were deflected to their HIV specialist. Co-participants also expressed their concerns that their primary care providers were not as knowledgeable about care guidelines for the management of HIV as they were and lacked an adequate understanding of their needs. These findings are troubling because primary care is the entry point to the health care system and is an essential health care service focused on disease prevention and management (Lofters, Guilcher, Maulkhan, Milligan, & Lee, 2016; Mukhi et al., 2014). In addition, the literature also explicates that many primary care providers and/or family physicians are providing substantial care for PLWH in Ontario (Kendall et al., 2015). A recent systematic review that investigated aspects of care valued by PLWH in high income countries reported how PLWH had challenges in their access to primary care services and how PLWH satisfaction of those services is poor

(Cooper et al., 2016). The findings in this inquiry support what is reported by PLWH in other studies (e.g., Cooper et al., 2016) regarding some of their unmet health needs and reduced overall access to primary care because of deflected health concerns.

Unmet and deflected health needs contribute to underuse of preventative primary care services and overuse of hospital emergency departments – a pressing policy and resource allocation issue (Jones et al., 2011; Lofters et al., 2016). The findings in the inquiry also align with the literature (e.g., Jones et al., 2011; Lofters et al., 2016, etc.) as co-participants elucidated how they have sought care in emergency departments because their needs were deflected in primary care, or because of acute exacerbations of other chronic health conditions with which the PLWH in this inquiry live.

5.3.2 Integration of Pharmacies and Pharmacists in Primary Care

The pharmacy is a unique health care setting because it is an open, public, and commercial space; it is unlike any other health care setting because patients do not regularly interact with the pharmacist in private, as they would with a treating clinician. Thus, personal health information and concerns are addressed publicly, and this public dialogue was a substantial contributor to the fear of inadvertent disclosure of their HIV status that could generate community-level stigmatization. In light of this finding, there are implications for policy and practice regarding how pharmacists interact with patients to preserve the confidentiality of health information in public spaces.

This inquiry illustrated how PLWH live with multiple, chronic health conditions, such as depression, schizophrenia, cancer, renal failure, chronic pain, osteoporosis and osteoarthritis, etc., all of which are treated with multiple medications that could adversely interact with each other if they are not closely monitored by a pharmacist and primary

care practitioner. Research conducted by Moore, Mao, and Oramasionwu (2015) found that polypharmacy, the use of multiple medications, increased with the age of PLWH compared to non-PLWH. While the findings of their research are based off of administrative data from the United States retrospectively in the years 2006 and 2010, the findings substantiate that ageing with HIV results in the development of multiple, chronic health conditions and polypharmacy.

Since 2012, pharmacists in Ontario have gained expanded scopes of practice, which include the initiation of therapy for smoking cessation, renewing and adapting prescriptions, and administering the influenza vaccine (Ontario College of Pharmacists, 2012). These regulatory changes signal the important contributions that pharmacists make to the delivery of health care and their value in primary care settings. In studying trust dynamics between family physicians and pharmacists within the community in Ontario, Gregory and Austin (2016) found that pharmacists were more trusting of physicians, whereas physicians based their trust on experienced competence with another health care provider. Although pharmacists are gaining more regulatory recognition for their knowledge and skills, if their enhanced skill sets are not recognized and utilized to the fullest extent by other primary care providers, then it is increasingly challenging to action the results of this inquiry and of others (see Bardet, Vo, Bedouch, & Allenet, 2015; Cope, Arcebido, & Trustman, 2015; Gentry et al., 2016; Tan, Stewart, Elliott, & George, 2014) to maximize the integration of pharmacists into primary care and achieve optimal outcomes for patients living with multimorbidity and polypharmacy.

Further or enhanced integration of pharmacists into primary care delivery is not a new concept, as there is a growing body of literature that supports it (e.g., Bardet et al.,

2015; Gentry et al., 2016; Tan et al., 2014). The role of the pharmacist has also been discussed in the context of harm reduction (Hammett et al., 2014) and HIV screening (Dugdale et al., 2014). Thus, pharmacists are essential health care practitioners who can enhance the value and quality of health care delivery. Recent research conducted in New York affirms that interprofessional primary care for PLWH, which includes pharmacists in the management of multiple, chronic health conditions, yields statistically significant favourable outcomes compared to non-collaborative care (Cope et al., 2015). The findings in Cope, Arcebedo, and Trustman (2015), coupled with the findings in this inquiry, support the need for increased education about the needs of PLWH. In addition, these findings also illustrate the importance and value that pharmacists add to primary care and health outcomes for people who take multiple medications to manage their health conditions.

5.3.3 Interprofessional, Collaborative Care and Ageing Within Communities

Patients living with multiple, chronic health conditions, or multimorbidity, benefit from interprofessional, collaborative care, rather than fragmented care from multiple practitioners who do not come together and create a care plan that builds on the strengths of each practitioner's knowledge and skills (Smith, O'Kelly, & O'Dowd, 2010; Wilson, Lavis, & Gauvin, 2016). In this inquiry, when co-participants spoke about the care they received, they provided statements about how their care does not align with the definition of interprofessional, collaborative care: "a type of interprofessional work which involves different health and social care professions who regularly come together to solve problems or provide services" (Reeves, Lewin, Espin, & Zwarenstein, 2010, p. xiii). Thus, sharing patient information – patient charts and medical records – with other

practitioners does not constitute interprofessional collaboration because the practitioners are not meeting and developing a cohesive care plan for the patient. This finding confirms problematic access to the most appropriate clinical care and indicates room for improvement in how health care services are delivered within suburban communities.

An essential component of high quality, interprofessional and collaborative care is that it is patient-centred (Shaw, 2008). As the personal health information of co-participants in this inquiry was shared with their health care practitioners, it is important to ensure that patients have access to their own records and health information. Access to a person's health information and records enhances their autonomy, and it allows them to track how their health conditions are managed (Rief et al., 2017). Moreover, this access could empower patients, increase their engagement in their care, and integrate their values and preferences into their care plans to facilitate their goals for ageing.

It was evident in this research that many of the health care practitioners who provide care for PLWH worked in isolation and did not reach out to other providers to work collaboratively to synthesize a course of treatment or management for PLWH. Part of this could be attributed to how many of the providers who cared for the same patients had their practices in different locations. This physical distance erects additional barriers to engage in interprofessional collaboration and underscores the relationship between transportation and access to care. This siloed structure of care resulted in PLWH repeating information in visits, despite the fact they were aware that their practitioners shared their medical records with each other, and this sometimes resulted in PLWH navigating the health care system without support or guidance from any practitioner. This repetition of health information is an inefficiency in care delivery and can influence and

affect the length of time a practitioner spends with a patient. Additionally, it can become a substantial time management issue when distributed against multiple patients. Not only can this can increase wait times and decrease the number of patients that can be seen by a single provider, but, over time, this could contribute to decreased access to care and unmet health needs within the community that the provider serves.

In this inquiry, some co-participants expressed how they experienced near misses in regards to medication errors. It is reasonable to speculate that if PLWH had better access to collaborative, interprofessional care, one or more of the providers in a multidisciplinary team setting may have caught the possible error because multiple providers are reviewing the care plan. Furthermore, the format of multidisciplinary care could also assist with the provision of quality assurance and enhance patient safety initiatives.

As the health care industry is witnessing the largest cohort of older age patients, emphasis on healthy ageing and ageing within communities is an important discussion topic (Jeste et al., 2016; Statistics Canada, 2015). In this inquiry, co-participants identified multimorbidity, transportation barriers, and unmet health care needs as a result of poorly coordinated care. These three themes substantiate the need for increased development of interprofessional community-based care initiatives to support PLWH and people living with multiple, chronic health conditions age within the community of their choosing.

5.3.4 Amalgamating Health and Social Care Delivery

Many co-participants expressed concerns over how fragmented social care supports from the government or community-based organizations contributed to their

decreased access to health care services. Overall, there were favourable statements made in regards to the social supports received from community-based organizations, such as the ACDR, but areas for improvement were identified (e.g., increased access to the volunteer drivers program, better organized community groups, increased user engagement and involvement in program planning, etc.). The findings in this inquiry reiterate the importance of reducing transportation barriers and increasing social capital and connectedness (Boniface et al., 2015; Mackett & Thoreau, 2015). Ultimately, these results add to the dialogue and vast body of literature on the social determinants of health (see Mikkonen & Raphael, 2010; Raphael, 2010) and the exceptional influence that social determinants have on health, well-being, and quality of life.

This inquiry aligns itself with literature that describes a fragmented coordination of care services for PLWH (e.g., Cooper et al., 2016; Laschinger, Van Manen, Stevenson, & Fothergill-Bourbonnais, 2005). As the needs of PLWH evolve from preservation of immunological function to coordinated health and social care for multimorbidity (Cooper et al., 2016), shifts in policy and care delivery frameworks should integrate social care services along with delivery of health care services. This change is essential for the achievement of desired health outcomes for the PLWH population, but also for those living with multimorbidity.

5.4 Conclusions and Opportunities for Further Inquiry

In summary, this inquiry explored the experiences of life with HIV in a suburban community and how health and social care services are accessed. PLWH in suburban communities experience stigmatization within health care settings and within their communities. PLWH experience transportation barriers, and these barriers can have a

significant impact on their ability to access care and achieve optimal health outcomes. PLWH live with multiple health conditions that are not managed in an interprofessional, collaborative manner. Moreover, PLWH in this inquiry identified the disconnect between health and social care service delivery, which reiterates the importance of the social determinants of health and a holistic delivery of services to support health and wellness within communities.

As there were no co-participants who identified as a current user of injection drugs or as transgendered, the experience of these PLWH in a suburban, Ontario, Canada community is one that still requires investigation and is an opportunity for further inquiry. In addition, an overwhelming majority of the literature consulted in the development of this work was conducted in the United States. This signals that further research needs to be conducted in Canada to understand the contextual differences between the two countries.

Appendix A: UOIT REB Approval

3/16/2016

University of Ontario Institute of Technology Mail - Approval Notice - REB Protocol 15-112



Derek Manis <derek.manis@uoit.net>

Approval Notice - REB Protocol 15-112

researchethics@uoit.ca <researchethics@uoit.ca>

Wed, Mar 16, 2016 at 1:31 PM

To: "Mr. Derek Manis (Primary Investigator)" <derek.manis@uoit.net>

Cc: "Dr. Brenda Gamble (Supervisor)" <brenda.gamble@uoit.ca>, researchethics@uoit.ca

Date: March 16, 2016

To: Derek Manis

From: Shirley Van Nuland, REB Chair

REB # & Title: (15-112) Accessing Health Care Within a Suburban Community: An Exploration of the Experiences of People Living with HIV

Decision: APPROVED

Current Expiry: March 01, 2017

Notwithstanding this approval, you are required to obtain/submit, to UOIT's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the research proposal cited above. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 (2014)) and the UOIT Research Ethics Policy and Procedures. You are required to adhere to the protocol as last reviewed and approved by the REB.

Continuing Review Requirements (forms can be found on the [UOIT website](#)):

- **Renewal Request Form:** All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed within 30 days of the expiry date will be automatically suspended by the REB; projects not renewed within 60 days of the expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
- **Change Request Form:** Any changes or modifications (e.g. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or Unexpected Events Form:** Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form:** This form must be completed when the research study is concluded.

Always quote your REB file number (15-112) on future correspondence. We wish you success with your study.

3/16/2016

University of Ontario Institute of Technology Mail - Approval Notice - REB Protocol 15-112

REB Chair
Dr. Shirley Van Nuland
shirley.vannuland@uoit.ca

Ethics and Compliance Officer
researchethics@uoit.ca

NOTE: If you are a student researcher, your supervisor has been copied on this message.

Appendix B: Letter of Invitation and Consent Package



RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

LETTER OF INVITATION

Title of Research Study: Accessing Health Care Within a Suburban Community: An Exploration of the Experiences of People Living with HIV

You are invited to participate in the research study named above. This study (#REB 15-112) has been reviewed by the University of Ontario Institute of Technology Research Ethics Board and was originally approved on March 16, 2016. Please read this form carefully, and feel free to ask any questions you might have of the Researcher or the Ethics and Compliance Officer. If you have any questions about your rights as a participant in this study, please contact the Ethics and Compliance Officer at (905) 721- 8668 x 3693 or researchethics@uoit.ca

Researcher(s):

Principal Investigator; Faculty Supervisor: Derek Manis, MHSc (Cand.) (Graduate PI); Brenda Gamble, PhD (Research Supervisor)

Departmental and institutional affiliation(s): Faculty of Health Sciences, University of Ontario Institute of Technology

Contact email: derek.manis@uoit.net; brenda.gamble@uoit.ca

Purpose and Procedure:

The purpose of the study is to understand the experience of how people living with HIV in a suburban community in Ontario, Canada access health and social care services. The research employs semi-structured interviews where you can speak with the Researcher about your experiences. The interviews are audio-recorded and will be transcribed verbatim; the principal investigator may also take notes by hand during the interview. It is anticipated that the interview may take approximately 60 minutes to complete.

Following the completion of the interview, it will be transcribed and available for you to review within three (3) days. You will have an opportunity to review the transcript, at your discretion, either in person or via email – please indicate your preference verbally to the principal investigator – to confirm meaning in statements and to provide additional information as you deem necessary. If you decide to review the transcript, it is appreciated to send your comments, changes, or approval to the principal investigator within seven (7) days; otherwise it is presumed that your experiences have been correctly described and captured in enough detail. This collaborative relationship of knowledge construction is quite important to the research process. If subsequent meeting is to occur in person, it will take place on a different, mutually agreeable date and time. This cyclical process may need to occur more than once, which is at your discretion, to ensure that meaning has been accurately captured and your experience sufficiently described in as much detail as possible.

Potential Benefits:

There are no direct benefits to you from participating in this research; however, this research can be used to inform healthy community design, reform to primary health care, and support the need for accessible, community-based care.

Potential Risk or Discomforts:

You may feel uncomfortable or embarrassed speaking about your experiences living with HIV and accessing health care in a suburban community. You do not have to answer any question that you do not want to. All data collected during the interviews are confidential and will only be accessed by the members on the research team listed on this consent form.

Storage of Data:

Recorded interviews will be transcribed on Google Docs within the Google Apps for Education on the UOITnet server and will be shared with the principal investigator and research supervisor listed on this consent form. Audio recordings will be deleted, and any hand written notes taken by the principal investigator will be shredded, once transcribed. Please do not use the real names of yourself or anyone else during the interviews. Raw data transcripts without identifiers will be kept indefinitely by the principal investigator on the UOITnet server.

Confidentiality:

Your experiences in accessing health and social care services will be collected for the purposes of informing the research questions and will only be shared with members of the research team listed on this form. Your privacy shall be respected. No information about your identity will be shared or published without your permission, unless required by law. Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct. For further information about security of data within Google Apps for Education, please visit <https://support.google.com/work/answer/6056693>

Right to Withdraw:

Your participation is voluntary, and you can answer only those questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research supervisor. You may withdraw at any time; however, honorariums are provided at the end of your interview. If you withdraw, your data will be removed and destroyed and not included in the research. You do not need to offer any reason for why you wish to withdraw your consent. Please note that it is difficult, if not impossible, to withdraw results once they have been published or otherwise disseminated. You will be given information that is relevant to your decision to continue or withdraw from participation.

Compensation:

You will receive a \$10 Tim Hortons gift card upon completion of your interview.

Participant Concerns and Reporting:

This research project has been approved by the University of Ontario Institute of Technology Research Ethics Board on March 16, 2016. If you have any questions concerning the research study, or experience any discomfort related to the study please contact the researcher(s) at derek.manis@uoit.net. Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Compliance Office (905) 721-8668 x 3693. By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Debriefing and Dissemination of Results:

A hard copy of the published thesis research will be given to the AIDS Committee of Durham Region and information on how to access an electronic version of the thesis will also be communicated.

Consent to Participate:

If you consent to participate in this study, please read the following aloud at the commencement of your interview when the principal investigator confirms your consent:

- I have read this letter of invitation and understand the study being described;
- I have had an opportunity to ask questions and any questions I have at this time have been answered. I know that I am free to ask questions about the study in the future;
- I agree that data collected during my interview will be kept indefinitely by the principal investigator listed in this letter and this data could be used for future research projects; and
- I freely consent to participate in the research study, understanding that I may discontinue participation at any time without penalty.

Appendix C: AIDS Committee of Durham Region Letter of Approval



AIDS Committee of Durham Region

Suite 202, 22 King Street West, Oshawa, Ontario, L1H 1A3

Phone: (905) 576-1445

Fax: (905) 576-4610

www.aidsdurham.com

info@aidsturham.com

February 4, 2016

Research Ethics Board
University of Ontario Institute of Technology
2000 Simcoe Street North
Oshawa, Ontario L1H 7K4

RE: Letter of Approval

"Accessing Health Care Within a Suburban Community: An Exploration of the Experiences of People Living with HIV"

To Whom It May Concern:

On behalf of the AIDS Committee of Durham Region, approval is granted to Derek Manis to conduct his master's thesis research entitled "Accessing Health Care Within a Suburban Community: An Exploration of the Experiences of People Living with HIV".

In speaking with Derek about his research, we have agreed to assist him in the following ways:

- Actively recruit five to 10 people living with HIV in the Durham region with whom Derek would conduct semi-structured interviews about their experiences in accessing health and social care services; and
- Provide a space for these interviews to occur.

We also have outlined our expectations of Derek, which include:

- Signing our volunteer code of conduct and confidentiality agreement; and
- Maintaining a standard of behaviour and comportment consistent with our expectations of volunteers while he is performing his research.

Thank you for your approval of Derek's research. We are pleased to assist in the contribution of new research to benefit the health and well-being of our clients.

Regards,

Adrian R. Betts
Executive Director

CHARITABLE REGISTRATION NUMBER 13692 6615 RR0001

Appendix D: Verbal Recruitment Script for ACDR Staff

VERBAL RECRUITMENT SCRIPT FOR ACDR STAFF

Co-participants must be:

- 18 years of age or older
- Living with HIV
- Residing in the Durham region (e.g. Pickering, Ajax, Whitby, Bowmanville, Clarington, etc.)

“If you are interested in speaking about your experiences accessing health and social care services in a suburban community, please contact Derek Manis, derek.manis@uoit.net, for further information on the study. The interviews will occur at the ACDR. Your participation is completely voluntary and does not have any bearing on your ability to access or receive services or goods from the ACDR now or in the future.”

Appendix E: Verbal Recruitment Script for Personal Networks

VERBAL RECRUITMENT SCRIPT FOR PERSONAL NETWORKS

Co-participants must be:

- 18 years of age or older
- Living with HIV
- Residing in the Durham region (e.g. Pickering, Ajax, Whitby, Bowmanville, Clarington, etc.)

“If you are interested in speaking about your experiences accessing health and social care services in a suburban community, please contact Derek Manis, derek.manis@uoit.net, for further information on the study. The interviews will occur at a mutually agreed upon location. Your participation is completely voluntary and does not have any bearing on our relationship now or in the future.”

Appendix F: Interview Guide

Question	Probes
Tell me about your experience accessing health and social care services while living in a suburban community?	<ul style="list-style-type: none"> • What is the experience like for you? • What emotions do you feel? When do you feel them? <ul style="list-style-type: none"> • How do they influence and affect your access to health and social care services? • How do they affect your overall health and well-being?
How do you access health and social care services?	<ul style="list-style-type: none"> • Which services and health and social care providers and services do you regularly access (e.g., doctors, pharmacists, caseworkers, ODSP, etc.)? <ul style="list-style-type: none"> • How did you learn or find out about these services? • How do you navigate through these services? Could you tell me about your experience? • How are these services important and necessary to how you manage your health? To how you manage HIV? • How do your health care providers communicate and share information with each other? How does this affect where and when you seek care? <ul style="list-style-type: none"> • How are they located in relation to each other, geographically? • How often do you have to repeat information or tests to different providers?
How does transportation affect how you access health and social care services in your community?	<ul style="list-style-type: none"> • What modes of transportation do you use to access health and social care services? <ul style="list-style-type: none"> • How often do you use each one? • Are there reasons why you would use one over the other? • How much money do you spend on transportation? Have you had to sacrifice in one area of your life to permit for transportation to access health and social care services? Could you tell me about an experience where this occurred? • How would you access those services if you could not use your preferred or back-up mode of transportation?

	<ul style="list-style-type: none"> • How do you think this would impact your health?
How does the structure or physical design and composition of your community, such as demographics, political ideologies, socioeconomic status, etc., affect how you access health and social care services?	<ul style="list-style-type: none"> • How would you describe the neighbourhood or community in which you live? • How long have you lived there? • How would you describe the people that live in your neighbourhood or community? • How do you feel in your community? <ul style="list-style-type: none"> • Do you feel as though you can be open and completely transparent with others about other aspects of your life and person, such as sexual orientation, religion/faith, ancestry or heritage, substance use – if applicable, etc. <ul style="list-style-type: none"> • How does this have an effect, or does this influence, on how you access care? • How would you describe social support within your community? • Do you feel isolated or excluded? If so, do feelings of isolation and/or exclusion lead you to use substances, such as alcohol, marijuana, tobacco, or other controlled or illicit drugs, to cope? How often do you use these substances? How do you feel this impacts your health and well-being? • Do you have an experience that you would like to share with me?
How does your experience of living in a suburb, which includes reflecting upon its culture and social norms, contribute to how you manage HIV and your overall health?	<ul style="list-style-type: none"> • How might you manage HIV and your overall health differently if you lived in a different community? <ul style="list-style-type: none"> • What characteristics – physical and social – would this community have that are different from the one in which you currently reside? How are these characteristics important to you? To your health? • How do you feel about accessing care for HIV, such as services from the ACDR, filling ARV prescriptions, visiting a dentist, pharmacist, or other allied health practitioner, etc.? Health or social care admin staff?

<p>How would you describe the treatment and reactions of health care providers in suburban communities when you reveal your HIV status to them?</p>	<ul style="list-style-type: none"> • Do you have a particular, memorable experience with any health or social care provider in the suburbs that you would like to share with me? <ul style="list-style-type: none"> • How would you describe their physical, observable behaviours and gestures before revealing your status and afterwards? • How would you describe their verbal and non-verbal communication before revealing your status and afterwards? • How did you feel in that moment when you told them that you live with HIV? How did you feel immediately afterwards, after leaving? • Did you feel like the quality of care you received was affected? If so, how? For better? For worse? • How often have you seen this health care provider since? • How did this experience affect where you sought health care? • How does it affect your decision regarding when and where to seek care – even if an emergent, life-threatening situation presented itself?
<p>Is there anything else that you feel I should know about your experience of living with HIV in a suburban community and how it affects your access to health and social care services?</p>	

Appendix G: Audit Trail of Themes Identified from In-Depth Interviews

Theme	Quotes from Co-participants
Intersectional stigma	<p><i>“And we still run into stereotyping, we don’t confide in a lot of people that we’re HIV, but they certainly find out that we’re gay, a gay couple soon enough. Ordinarily here, it’s not an issue in Oshawa when I first moved here it was more prevalent people would hassle you.” (Cp03)</i></p> <p><i>“Yeah, I’ve found that if I do tell somebody that I’m HIV, it’s rather meaningless to them, but if I say I’m gay, oh that’s a whole different thing.” (Cp03)</i></p> <p><i>“Ah, discrimination, other than just a couple of phone calls and people that here in Oshawa that have found out that I am gay, they tease me and make fun of me.” (Cp08)</i></p> <p><i>“Well, I don’t mind people knowing right away that I’m gay, but it’s just trying to get the HIV, Hep C out of my mouth. Because if I do that, people want to beat the crap out of me, do this and that to me, treat me like garbage. It saddens me. It really does. It pisses me off that, you know, it’s a new millennium and people should not be that paranoid and scared of HIV and Hep C.” (Cp08)</i></p> <p><i>“I was just riding my bike and the guy stood in front of me. He said, ‘you have HIV and I want to kick your ass.’” (Cp08)</i></p> <p><i>“Yeah, if I, for instance, if I call to see or set up an appointment to see an apartment and they ask me to tell them about myself and I don’t have nothing to hide; my life has always been an open book. The second I mention gay, ‘oh, well, if you’re gay then you’ve got this and that’, and I’m like, ‘I’ve got your phone number. You want to discriminate me because I’m gay, because I have HIV and Hep C, you’re going to get shut down because I’m going to contact the MP. Click.’” (Cp08)</i></p> <p><i>“It’s almost like they’re trying to corner us, pick us all off one at a time to get rid of us. They think maybe they could get rid of the gay community, then they’ll get rid of HIV, AIDS and Hep C, not realizing that there is a lot of straight people that don’t realize it’s not just gays anymore it’s straight people too. And that’s the biggest problem that I have, trying to explain to people that it’s not just gay people: it’s straight female women and prostitutes, straight men that just don’t give a damn and want to give up on their life so if their life is miserable, they’ll make everybody else miserable.” (Cp08)</i></p>

	<p><i>“If I wasn’t gay, I wouldn’t have any problem whatsoever. There’s a 99 per cent chance I wouldn’t have any of the problems I’ve had with regards to being HIV positive” (Cp10)</i></p>
Stigma	<p><i>“I’ve told my family and a few close friends, but no one else. I’ve told people before and never heard from them again. So I just don’t want to go through that again.” (Cp01)</i></p> <p><i>“No one else responded, and I was told, ‘we have tried in previous years, at ACDR, to get gay a men’s group. We get two or three guys interested and it peters out. And the reason is: a lot of men don’t want to be seen going to ACDR.’ So our groups were amalgamated and they had it offsite.” (Cp01)</i></p> <p><i>“We’re tolerated. I think a small part of it is the fact that my partner is blind and people are terrified of people being blind. They tend to run screaming. It’s so boring and so ridiculous. With him hanging off my arm all the time in public, we get enough stares because people are trying to figure out what’s going on before they see him cane. I don’t need people going ‘Oh my God, it’s an alien!’” (Cp02)</i></p> <p><i>“the HIV specialist I had at Lakeridge Health, Whitby, he was very well known at Rouge hospital just west of us as well as at Lakeridge Health here. He had a big clientele. And there would be candidates with all sorts of infectious diseases besides HIV and he even had clinics in Africa so everybody made the assumption that everyone who came to his clinic, even there in Whitby, was HIV.” (Cp03)</i></p> <p><i>“Yes. There’s a and it’s gotten worse in the past couple of years because they’re worried about opioids and painkillers and not the real hardcore meds for HIV, but they’re worried about you, they’re categorizing you and stigmatizing you with, perhaps, an issue with drugs.” (Cp03)</i></p> <p><i>“Yeah, they’re not. It may be still because they don’t want to be identified coming into this building or going to pride, say, or anything to do with anything local it’s still a small town here, even though we’re GTA. They like to go to Toronto on the weekends and carry on.” (Cp03)</i></p> <p><i>“They had a great deal of difficulty dealing with my choice of lifestyle, dealing with my choice of partner, dealing with my disease HIV, dealing with my awareness of the gay community</i></p>

	<p><i>and participating in LGBTQ activities, they just have a real difficult time with it. They don't like to talk about it, they don't like to hear about it. It took a long time for them to recognize my partner.” (Cp03)</i></p> <p><i>“Oh yes, should be thoughtful and respectful and all that and she wants absolutely nothing to do with me. She won't talk to me at all, it's like I'm the black sheep of the family. It got so bad at one time that I couldn't even touch the children, or when they came to my mom's house and I was living at home they brought their own dishes.” (Cp05)</i></p> <p><i>“Little smirks or something in the store. Somebody will look at you funny or something. A redneck or something like that.” (Cp05)</i></p> <p><i>“My older sister broke my heart. She told people living in that building who are nothing but welfare mentality, uneducated, started a petition that went like wildfire trying to have me kicked out of this town. There was over 10,000 signatures in less than a week. I couldn't even go outside my door. People were throwing eggs at my house. It was bad. You think any of the neighbours that live here, ok there's been a few families move in that weren't here, but everyone else remembers. They don't even - I could sit outside and my neighbours, the ones that don't know, they'll speak to me, and the ones that do know, if they see them talking to me, they'll say, 'oh don't go near her, she's got HIV’” (Cp06)</i></p> <p><i>“A suburban area where there's lots of discrimination, insults, having to get in fist fights to protect myself.” (Cp08)</i></p> <p><i>“From being at the shelter. Because at the shelter, if you're not - the walls are like paper thin so everybody finds out. And before you know it, within 15 minutes, everybody looks at you like you're diseased.” (Cp08)</i></p> <p><i>“It depends. It depends on where you are. I've had people where it didn't faze them, I've had others where they pretended it didn't matter, but it did.” (Cp10)</i></p> <p><i>“A hostel at the bottom of Church Street, a youth hostel at the bottom of Church Street in Toronto. I identified as being HIV positive and they told me, 'we don't think this is the right place for you.’” (Cp10)</i></p> <p><i>“I still feel there is so much ignorance and I still feel there's so much blame. That's the part that's sad because people don't know</i></p>
--	--

	<p><i>how you got infected, but there's still the question of 'how did you get that?' and other stuff." (Cp13)</i></p>
Stigmatization – Health Care Settings	<p><i>"he just said, like I was, 'a walking piece of meat,' and that 'I should be dead in a locker.'" (Cp03)</i></p> <p><i>"Several times at Lakeridge Health, Oshawa. I would go to the emergency department and there was no privacy there. And the nurse tried to talk through the glass and she would be screaming everybody sitting there waiting to be to get help and they would hear." (Cp03)</i></p> <p><i>"So, in particular, HIV, I haven't had a 'no' because of HIV. I have heard 'no' saying that my dental benefit is ODSP. I don't know why. And sometimes that dialogue has been, "well, ODSP is only going to cover one visit per year, and for you to enroll as a new patient, we're going to need to see you at least twice: the initial visit is an assessment, the second one practical services. And one of those is not going to be covered and it's going to be this much money." So it's not even so much that they're saying 'no' in that circumstance, but just that the money is prohibitive. The expense is prohibitive." (Cp04)</i></p> <p><i>"For example, I was at a clinic and they had an intern student. Like a student. A student nurse. And I knew on my profile indicated that I was HIV positive. So she sat down and she's getting ready to take my blood and wasn't wearing gloves. Literally was at the point of going to and she happened to turn to the profile screen and she stopped. And I saw what she was looking at on the screen: it was my profile. She stops, and she doesn't go and get gloves. She actually went to the senior staff person to ask how to deal with the situation." (Cp04)</i></p> <p><i>"Whereas the doctor who had given me those forms, it wasn't so much a my interpretation wasn't so much as a, like a response to the HIV, but a response to he asked me some personal questions, like the icebreaker sort of questions: 'You're married?' 'Yes, I'm married.' 'Do you have kids?' 'Yes, I have a son.' 'How long have you and your wife been together?' That kind of stuff. So then we got more shifted to he did the examination and conversation shifted to more medical questions, one of them was anything he should be aware of. I said, 'well, you should know that I'm HIV positive' So he kind of did that double check and said, 'but you're married. 'Yes, I'm married.' So then he says, 'so how did you get HIV?' ... it clearly illustrated a 'how can you be married to a woman and have caught HIV?' But again, it's not a question you</i></p>

	<p>would expect to be faced with from a doctor. It felt kind of intrusive, or more that he was making interpretations. And ultimately how I contracted the virus really doesn't matter to what precautions he needs to take as a doctor, right? Whether I contracted it through MSM or through a blood transfusion or whether I contracted it through needle use, what he needs to do as a doctor is the same, right?" (Cp04)</p> <p>"Yeah, yeah. He wasn't very understanding at all. And then I had a family physician that basically told me that he can't treat me because he doesn't treat people with HIV, so then I had to find a new doctor." (Cp05)</p> <p>"None of us want to go to the hospital. We get treated so bad not even like we're human. It doesn't matter what hospital; it doesn't matter where. It's despicable and I was a nurse for 25 years. It makes me ashamed." (Cp06)</p> <p>"I'm fighting with the EMTs saying that I'm not going because we're treated so poorly that I don't want to have to deal with it." (Cp06)</p> <p>"Well, one doctor up there at the hospital, remember I told you? And I was in a lot of pain. I broke something, and he refused to give me anything because being HIV positive is written right on the front page and he figured, I mean, he's a doctor, he should know better, he just figured that because I had that that I've been a junkie. I was angry and I broke down and told him how I got it. I said, 'you're a doctor, you should know better'" (Cp06)</p> <p>"I don't go anywhere near a walk-in clinic." (Cp06)</p> <p>"But, anyway, this one day, this one PCW came, and then she wouldn't come back and I didn't understand or know what was going on. I liked her. She came two or three times, and then she refused to come anymore" (Cp06)</p> <p>"In Port Perry, they look at me like I'm diseased." (Cp08)</p> <p>"I've actually wanted to smack my family doctor in Port Perry because when he found out that I had HIV his eyes widened up: 'Oh, we don't get your kind around here that much.'" (Cp08)</p> <p>"I didn't feel comfortable in front of the doctor. I was living on farm in Sunderland with a guy by the name of Mike and he was with me and the reaction that I got when I mentioned that I've got</p>
--	--

	<p><i>HIV, I sort of looked at him and then looked at Mike and I said to Mike, 'it's time to leave. Like I'm dead serious, it's time to fucking go.' I said, 'no, it's time to go, otherwise I'm going to stab the doctor.' I said, 'I'm not threatening you, you look at me like that or treat me like that one more time because I have HIV and Hep C, I'm not going to hit you, physically, I'll take you to court for discrimination.' That's bullshit." (Cp08)</i></p> <p><i>"I went in last year for pneumonia. The doctor walked into my room and said, 'so, you have AIDS.' I said, 'no, I'm HIV positive.' 'No, no, you have AIDS.' I said, 'no, I don't. Check your books: my numbers are above 200, my CD4 counts and viral load are normal.' And he said, 'ah, fine, but you have PCP pneumonia.' I said, 'alright, well, don't I need a bronchial tube to confirm it?' And he said, 'oh well we don't do that unless you get worse.' And then I said, 'well you don't know I have PCP pneumonia because it has to be tested to confirm PCP pneumonia.' And he said, "no, no, but it just looks like it." (Cp09)</i></p> <p><i>"Like I said, St. Catherine's, a little different. It's a lack of pure education in that whole region of Niagara where they'd say, 'oh, really, oh' and take a step back. And one doctor said, 'oh, you don't look that way.' 'Look what way,' I said? 'Well, you know, gay.' And I said, 'what does gay look like?' (Cp09)</i></p> <p><i>"I went in for bronchitis or pneumonia again, and the doctor stood at the foot of my bed and looked and peered over the bed and said, 'ah, looks like you have pneumonia.' He never touched me. He never examined my chest. He never even ordered an x-ray. But he said, 'yeah, it looks like you have pneumonia.' (Cp09)</i></p> <p><i>"One of my best friends, who has passed away now, he was sitting in the doctor's office waiting area and the doctor walked out and said, '[Friend's name], you have AIDS,' and turned around and walked out. And he was left there crying. And I'm going, 'are you fucking kidding me? How insensitive?' (Cp09)</i></p> <p><i>"Yes, at my dentist's office. I was bringing one of my forms for her to sign because it was easier for me to get the signatures then to confirm that I actually went to the appointment rather than to wait for the audits. And this girl just sat there and started flipping through -- this is one of my heavy months when I have like 24 pages of documents and she started skimming through them. I said, 'excuse me, what are you doing?' She said, 'nothing, I'm just looking at what I'm to be signing.' I said, 'I've told you what and where you're to be signing. You have no right to be perusing</i></p>
--	---

	<p><i>through the rest of those pages that's my private information. All I've asked you to do was to sign to verify that I was here on your space right there that I just pointed out to you.' She said, 'yeah, yeah, yeah, ok,' and she kept flipping through the pages. I said, 'May I have my documents back?' It didn't go over well. She was looking at information from the naturopathic clinic at 333 Sherbourne Street where it said I'm HIV positive.'" (Cp10)</i></p> <p><i>"One of my teeth started to hurt. I don't know if it was because I had never experienced the cold or what it was. And I didn't know any other dentist I only knew of it because it was where I processed my refugee medical assessment. So I decided that I was going to go as a walk-in and I told them that I didn't have an appointment, but this was what was happening. I told them up front that I was poz. The reaction, if looks could kill, they were so scared of me. He put me in a chair and looked and didn't do anything. And then he goes, 'oh, we wouldn't be able to do anything at this time. We're full, but I could write you prescription or maybe recommend another dentist.' I was like, 'ok.' He was so scared of me.'" (Cp11)</i></p> <p><i>"I went to the medical clinic and I saw this doctor. I saw two doctors there before, no problem. And I saw him and I was so freaked out about me. Before he even shook my hands he put on gloves. And I'm looking at him and smiling to myself and he didn't have to examine me or anything because I was just there to get a refill for my prescriptions and I asked him something and we were talking and I told him, I think he asked me what meds I was on. And I was telling him and asking him if he thought it was because of that and he put on the gloves right away.'" (Cp11)</i></p> <p><i>"[My doctor] referred me to a dermatologist there. And he had a strange name. You could see he was one of those orthodox Jews who grow their beards. He treated me like a bug when he saw me. He'd go, 'stand there!' and look from far and didn't touch me or anything. And then he wrote the prescription and handed it to quickly, like just go! I told him I'd never go back until I find this one at the Oshawa clinic. Never went back.'" (Cp11)</i></p> <p><i>"So, it's strange that I, like I told you, I wasn't on meds first, and I got really sick, and I was at the emerg like three or four times in one month. The thing is, when you go to emerg, there's a sitting room there and the office there. And you go in and tell the nurse if you've ever been there, what's your ailments, stuff like that. And I went in there and I was sitting there and there's the sitting room right opposite. And she was asking me if I have a fever and if</i></p>
--	---

	<p><i>there's anything else, and I said, 'oh yeah, I'm HIV positive.' And she said 'HIV?' like shouting it out. I was so embarrassed. So stuff like that, you always have to look, and it made people scared because the reaction that you get sometimes from medical professionals -- shouldn't you know more about this than I do? It's 2016! Do you have to be that scared of somebody or be so closed-minded? Like, come on! This is not the 80s where everyone was so scared and we didn't know what exactly it was. You know this 2016 and these are people who are trained medically, and you've got to leave it to people who don't know anything in my country that it's this fear, you know? And you're thinking that the medical thing, it would be different, but some of them are more scared of you than anything."</i> (Cp11)</p> <p><i>"So I went in, and the nurse that was there, she kind of looked at me, she looked back at my papers and she saw that I had HIV and made this really gross face. She started reading my information out loud in front of other people. That really struck me and really upset me because we live in a world that has stigma and discriminates against people living with HIV. People look down on you and act like if they touch you or hug you that they're going to catch it, but that's not how it works."</i> (Cp12)</p> <p><i>"So I already had that bad experience in Ajax. It is a little bit hard, I am still searching for which labs to go to here in Oshawa, and which services to access because it's hard I don't have to have that same experience again"</i> (Cp12)</p> <p><i>"No, I wouldn't access anything here. I just don't feel like they I just feel like up here there still needs a lot of improvements from the people who are still scared."</i> (Cp12)</p> <p><i>"When I was diagnosed with HIV, I remember being there and the nurses were reading my information. I remember one nurse in particular, she was just disgusted by me; she wouldn't even come close to me, she would do everything from far away. So for me, that really I remember crying really bad that day. Like, this is how it's going to be from now on, how people are going to look at you, like you're some sort of disease and they just won't come near you. It's hard."</i> (Cp12)</p> <p><i>"I used to feel stigmatized and felt like I was treated differently. I also felt that there wasn't enough confidentiality because you would find your documents lying all over the place."</i> (Cp13)</p>
--	---

<p>Fear of Disclosure</p>	<p><i>“But I don’t freely share it with a lot of people. I would say out of my friends, maybe 10 per cent of the people know. My neighbours don’t know. People around me don’t know. I have volunteers who come to my home and help me out and I don’t tell them.” (Cp01)</i></p> <p><i>“There’s one person I know who’s quite sexually active, and he’s told me about all the people he’s slept with in Durham who are trying to show that they are straight, but they’re not” (Cp01)</i></p> <p><i>“I don’t think much anymore. But initially, that was the issue was, we would run into people that we’ve had relationships with not long lasting and then to find out that they were straight with families and married and children and worked at GM and so on living here in Durham that came to a support group and didn’t realize what they were going to meet and who they were going to meet. So it was rather like outing them. And that would happen sometimes at the doctor’s office or at the hospital.” (Cp03)</i></p> <p><i>“Again, so I think your first question was, ‘how do I identify?’. I identify as straight because I’m in a marriage with a woman. Although my history, and certainly how I probably contracted the virus, was through MSM. Orientation is not actually a question I’m comfortable with, more because I’m not comfortable with the labels and I don’t think labels work well. Also because labels aren’t a one-size-fits-all. Most funding in the AIDS Service organizations is for the LGBTQ, which, I mean, there’s real concerns: it’s a high risk population” (Cp04)</i></p> <p><i>“But, yeah, it’s, I guess it’s because I’m afraid of my understanding is that you have to disclose, and there’s a form, if they use a standardized form the last one I filled out in Toronto asked specifically about HIV. Different people have suggested to just ignore the question, don’t answer, don’t disclose.” (Cp04)</i></p> <p><i>“I think this is harder in Durham region...not that confidentiality isn’t prioritized, but that there are such limited treatment and social outlets.” (Cp04)</i></p> <p><i>“Similarly, going to the Positive Care Clinic, I’ve run into friends and acquaintances who definitely don’t know my HIV status...yet they serve as volunteers at the Lakeridge Health building. To my knowledge, the only other health services available at this location are rehabilitative, which I clearly wasn’t in for. So, in such a circumstance, have I again outed my HIV status? I think anonymity in Durham can be harder to preserve.” (Cp04)</i></p>
---------------------------	--

	<p><i>“We’re a low profile we’re just your normal people. On the street, people think that [he] and I are brothers. They met our mom and dad, and why tell them anything different, if that’s what they think. [He] and I both look alike, we’re both basically the same age, and if they were to ask, I’d say I was adopted, simple as that.” (Cp05)</i></p> <p><i>“Yes. I spent a whole well, growing up through the 70s and 80s hiding your sexuality, I’m over it. If you don’t like it, screw off.” (Cp09)</i></p> <p><i>“Most times you don’t even want to disclose. I usually wait until I’m in the room with the doctor, personally, instead of telling the receptionist or writing it out, and then I let them know.” (Cp11)</i></p> <p><i>“I was sharing a condo with some friends and I was poz and I wasn’t on meds yet. And I was thinking that I hope I don’t have to go on the medication that you have to store in the fridge because then they would know. So the thing was, when I got so sick, I had to try and hide it, but then in the morning I had to ask one of the girls to drive me to the emergency room. And then I had a family friend that if something was wrong, I would call her and ask if she could drop me, you know? Or I’ll just call the taxi if I don’t want people to know.” (Cp11)</i></p> <p><i>“And, for me, it’s still quite hard disclosing my status.” (Cp12)</i></p> <p><i>“Like, for me, living here it’s hard. Getting around, I wish I could just get on the bus and get to the labs here and find a doctor that’s the hardest thing living out here. But at the same time, I’ve got to do what I’ve got to do to try and keep myself safe and not disclose where I don’t think everybody needs to know.” (Cp12)</i></p> <p><i>“So the reason why that I feel that I’m alone, just tossed out here, I don’t have the support or can just go to a group and meet other people like myself, because I’m just so scared to disclose myself with what I’m living with. I’m scared. I don’t know how they’re going to view me. I know there are other people out there who have the same thing, living with HIV. ACDR has groups, but I don’t want to attend because I’m scared of who I’m going to see there. If someone is going to say something or recognize me and out my status, because that has happened before” (Cp12)</i></p> <p><i>“At first I was scared because I didn’t know what to think. I was very, very nervous going to my first time to meet him, but he turned out to be a great dentist. He goes, ‘you know what, I see a lot of people like yourself.’ Everything is clean and sterilized and</i></p>
--	---

	<p><i>he said not to worry about infecting anyone because it's his job to worry, not my job. But anyways, it still scares you. You still feel like, finding a dentist, finding a lab, finding a doctor, out here it scares you because you don't know how people are going to look at you and react. Because there's still people out there that think by touching you or drinking from the same cup as you that they're going to get it, but that's not how it is. So people here are not well educated, you know?" (Cp12)</i></p> <p><i>"I've got to do what I've got to do to try and keep myself safe and not disclose where I don't think everybody needs to know." (Cp12)</i></p> <p><i>"I would go to my doctor downtown because I have gone to doctors out here. In Ajax, I went and I was so scared to tell him my status." (Cp12)</i></p> <p><i>"I recently started going to Lakeridge, I was very reluctant because this is Durham, even though I've only had good experiences and good things to say about Durham. But because this was brand new, and also because of where I work and where I go to school, I have to work in the health department at [name of employer]. And I say to myself that this may be complicated because what if I come across some of the people that I work with. And I was very reluctant to make that decision and find a doctor here. But after I did, they did ask me the thing you're asking me now if I had any concerns, and I said my concern is running into people I know because of the stigma and I don't want to have to explain myself as to why I'm here etc." (Cp13)</i></p> <p><i>"So I was very, very pleased with the way they handled it because they could see that I was really concerned about, you know, I didn't want any kind of disclosure, because I said I'm not willing to do that I don't want to do that. In the past, I had a bad experience with that." (Cp13)</i></p> <p><i>"even if I was going to the ACDR, and I realized because of where I work now, there's people who volunteer there from where I work, so I didn't want to be running into them. But it was good in the end that we didn't end up going there" (Cp13)</i></p> <p><i>"I would like to volunteer whenever I have time, now I can't because I don't want the association. I guess the bottom line of what I'm trying to say is the stigma is still there, and, for instance, when I'm in the college, with the course that I do, discussions come up and you hear the comments that people make about HIV and AIDS and how nasty it is and all sorts of things that they say,</i></p>
--	---

	<p><i>how they would not want to be around a person who is I'm sitting right there and I'm listening and I realized that no matter how long this has been around, people are still quite ignorant and afraid of this disease. And you can't begin to imagine"</i> (Cp13)</p>
Pharmacies	<p><i>"When we first started getting HIV drugs up at the Loblaws pharmacy there, the first time was like, 'what's going to happen?' ... I've heard stories of people having some trouble with attitude and stuff."</i> (Cp02)</p> <p><i>"So I didn't really run into conflict until I started dealing with local pharmacies because they always don't stock what you need, they have to order it in special and they don't always keep it in stock either because they don't have many clients that are HIV. And you try to talk to them to explain the situation that you may need this or that, and they're not keenly aware of all that a person with HIV would need, and I would have to inform them."</i> (Cp03)</p> <p><i>"They just didn't have what I always needed. I used to deal with the one in my family doctor's building, but they were of the same nature. And I didn't like them to talk openly about it, in front of everybody."</i> (Cp03)</p> <p><i>"It doesn't give you much privacy. Even if they didn't know what they were mentioning about my meds."</i> (Cp03)</p> <p><i>"Oh I still think there's a lot of education needed. Not so much with the caregiver, but the pharmacists who work different shifts."</i> (Cp03)</p> <p><i>"And I was getting frustrated because they keep nickel and diming me about my meds. I used to get them from pharmacy.ca and I would get three months worth, and I managed mine by putting them in all the little dosage containers, and so I would know what I would take per day and how much. And they would only be giving me, like, only a month's supply. So here I am, running out back and forth trying to get my meds, and meanwhile, they're charging for every dispensary fee they can because they're giving me such small dosages."</i> (Cp03)</p> <p><i>"It's really every experience where I've gone into a pharmacy, you can appreciate, typically, you are seeing a pharmacy assistant as opposed to the pharmacist. I'm on one of the new cocktails of meds, and I don't think it's in the regular vocabulary of the pharmacy assistants, so they almost without censoring "Oh? What's that for?" You know, and there could be people there</i></p>

	<p>around, so you feel, “oh my goodness!” You look for times when there aren’t other people around. So I might circle a little bit before I go to the counter. If they don’t know what I’m trying to get filled, or if they’re not couth enough to be discrete enough.” (Cp04)</p> <p>“I was in one pharmacy and getting a full complement of meds filled so my HIV meds, my antidepressants and I was actually told to go get my prescriptions filled elsewhere. They didn’t volunteer a reason why, nor did I ask because it was so surprising. The easiest interpretation of that is one of stigma or something akin to that. But again, that’s just an interpretation, right? And like I say, the easiest interpretation of being sort of told to get your prescription filled elsewhere, you do this double-take and move to, ‘well, was I behaving in a way? Am I so...’ I think I present as a quiet, unassuming -- I’m not an aggressive person, but you start to wonder: what’s going on? Am I misinterpreting? Is my body language saying something different? You know? You really start to question what’s going on. But the easiest interpretation is that they weren’t comfortable with me as a client, whether it was for mental health the antidepressants, or the HIV meds. Those are the only two things that I could see, so definitely you’re not going to go back and subjugate yourself to that again, no.” (Cp04)</p> <p>“Yes. I get my meds three months at a time. And having just moving recently, for some reason, I thought I had an extra month of because it comes with a bottle per month I thought I had another bottle not unpacked yet, so I wasn’t terribly concerned that the one I was currently on was almost empty. As it turns out, I realized on a Friday night that I was out of meds. And normally you could go to a Shoppers or a Lovell Drugs or something, and you know they’re open on a Saturday in the case of Shoppers, they’re open Saturday and Sunday. But I won’t go there. So I had Saturday and Sunday without meds because the courier pharmacy that I use, they don’t have hours on Saturday or Sunday.” (Cp04)</p> <p>“A pharmacist at a certain pharmacy. I thought about maybe changing my medication and having it all go there it’s closer to my house. And I thought I might do that. It’s a brand name pharmacy the biggest one there is. And the pharmacist just kind of shied away from me when he found out what kinds of medications I was on and started asking questions out loud, ‘What’s your count? When did you get HIV? How long have you had HIV?’ There’s customers around and he’s supposed to be keeping this quiet. You don’t do that. You don’t talk loud about things that are supposed to be confidential. And it even says confidential area and</p>
--	---

	<p>he's loudly saying, 'And how long have you had HIV? What pills are you on? What's your count?' And he was just so obnoxious, but I didn't tell him, 'enough's enough, you're being too loud.' He wasn't shy about it at all. 'Oh you're on a lot of different medications? What are you on all this stuff for? What are you on this here for? And why do you do that, what's the problem here?' He didn't take me into a room or nothing; everything was done out in the open and there's people behind me. He yelled, 'HIV' and, 'How long have you had HIV? AIDS!' And I'm just like, 'Oh God.'" (Cp05)</p> <p>"A pharmacy in St. Catherine's would fill – I'm on three HIV medications – they'd fill two of them and then say, 'call us when you're out of the third one.' If I run out of all two, that means the third one's out too because I'm taking them all at the same time. And then they'd be like, 'oh' and then they'd put a rush to fill the order. So it's a lack of pure education." (Cp09)</p> <p>"The pharmacy in St. Catherine's was like, 'oh, it'll be no problem.' It was actually recommended by the agency in St. Catharine's, in Niagara, because everyone fills their medications there. And after getting there, they would over order one of my medications. So I would have two months back up on one, and I'd run out of another within that two-month period that they're over with. And they wouldn't sit down and talk to me and say, 'ok, what do you need to make sure that all of them need to be at the same level?'" (Cp09)</p> <p>"I was terrified because I was so scared. You know how sometimes the pharmacist calls you to the counter when your meds are ready and then, "oh, have you taken this before?" and then when you say no they start reading what could happen and the drug's name is so and so, and I was so terrified the first time I filled my prescription. Oh my God, oh my God, I was just hoping please don't do that, please don't do that. And it just so happened that when she called me up I was the only person there, but knowing that I had this fear." (Cp11)</p> <p>"Also, there was this question of let's say you have to pick up medication and the kind of medication that you would have to get from the local pharmacies within the neighbourhood. So I had concerns about that." (Cp13)</p>
Deflected care	<p>"My family doctor openly admits that the knows nothing about it, and any time I come with an issue, a physical issue, he'll send me</p>

	<p><i>to a specialist, specializing, say in that part of my body or that particular situation.” (Cp03)</i></p> <p><i>“Yeah, you have to know what HIV drugs you’re on and what can affect their effectiveness by taking anything else...And as they say, ‘it’s your responsibility,’ and that’s a real effort to maintain especially now that I’m 26 years with this” (Cp03)</i></p> <p><i>“Accessing health care that, my personal interpretation, is not related to HIV is often challenging in the sense that when you see a family health practitioner, and you disclose your HIV status, they automatically assume that whatever health concern you’re presenting is HIV related and so direct you to go to the HIV care clinic as opposed to addressing flu symptoms or whatever else it is that you’re going in for: you know, migraines in one case, or digestive problems, or swallowing problems that I’ve experienced, which, speaking to my HIV peer network, doesn’t seem to be related to my HIV status, but approaching family physicians, or urgent care clinicians” (Cp04)</i></p> <p><i>“I would loosely say yes that there was a stigma, more so I felt it was clinical, that they use medical speak to sort of create a separation. And just for clarification, it hasn’t just been doctors. Trying to find a doctor...having relocated and needing to find a family physician, it was challenging.” (Cp04)</i></p> <p><i>“So in the interim, I was enrolled in a nurse practitioner program. Specifically, through a peripheral health concern of mental health, suffering with depression, that sort of gave me an entrance into what became a substitute for a family medical care. But again, most things that I presented in those appointments, were largely ignored or it was suggested that I review those with my HIV specialist.” (Cp04)</i></p> <p><i>“you have access to volunteer driver programs, but they like to schedule that in advance. And as you sort of interpreted, my routine HIV appointments were easy to schedule a volunteer driver for, but when going in for a more urgent or immediate health concern and you’re being deflected to your specialist, that’s not always falling into a timeframe where the volunteer drivers can be scheduled.” (Cp04)</i></p> <p><i>“If I would go and this is what I would say one of the ongoing issues was a swallowing issue. They would try and refer me to somebody within their like they seemed to have a preferred list of partners. But they wouldn’t do the scheduling. They would pass</i></p>
--	---

	<p><i>your information along and these partners were supposed to call you to schedule directly never, ever worked. Ever.” (Cp04)</i></p>
Education about HIV	<p><i>“Still have to let Urgent Care, Dentist & Optician know to take precautions; even at Princess Margaret Hospital in Toronto when I had my eyes tested.” (Cp03)</i></p> <p><i>“To make them more aware of that we are eligible for the same care everybody else is and it’s not as frightening as you think.” (Cp03)</i></p> <p><i>“That’s exactly right. Exactly. And if they were also educated enough about what PHAs need.” (Cp03)</i></p> <p><i>“Even to this day I have to get them to brush up on their skills that I am HIV” (Cp03)</i></p> <p><i>“And they didn’t understand they didn’t think my HIV had anything to do with the rest of my body, it was just they were after this tumour that was there and they wanted it out.” (Cp03)</i></p> <p><i>“Even picking a regular dentist, you have to remind them too and to wear gloves because you are of HIV status and so on. And they’re not always aware of see when you go to the pharmacy now, they’re not always aware of what they offer to you that could affect the effectiveness of your HIV meds.” (Cp03)</i></p> <p><i>“It used to really, really, really bother me when I would disclose at the hospital, if I was in for whatever reason -- an emergency stop or something scheduled. When the people would actively -- you’re not supposed to actively cap a needle. It used to really bother me when they would do stuff like that. I would really affect me.” (Cp04)</i></p> <p><i>“Embarrassed, but not really embarrassed because people are just ignorant and don’t know things. I’ve got a sister-in-law who is a head nurse in Peterborough and she won’t have anything to do with me; she wants nothing of it. She thinks it’s a terrible disease and wants nothing to do with me.” (Cp05)</i></p> <p><i>“It’s ignorance! It’s ignorance. That’s all it is, you know what I mean?” (Cp06)</i></p> <p><i>“I think a lot is due to education.” (Cp09)</i></p>

	<p><i>“I’ve heard a lot of horror stories from people in the same situation: being HIV positive in a small town where there’s a lack of education, lack of treating people with respect.” (Cp09)</i></p> <p><i>“Going online and talking to guys, especially myself being poz, and people that have in their profile that they’re into, say, barebacking, unsafe sex, and then they find out you’re poz, and they drop you like a hot potato because they’re in a bi relationship. And for me, it doesn’t make any sense that you’d put your partner at risk and if you knew the consequences of what your ass is out there is no cure for HIV and some people think there is.” (Cp09)</i></p> <p><i>“I haven’t really dove myself into the gay community here. Like, I haven’t been to 717 or any other gay things, like pride Oshawa. I’ve meet gay people within the city that have been really friendly, and others that have been just down right rude, and I think it just comes down to lack of education.” (Cp09)</i></p> <p><i>“No, I wouldn’t access anything here. I just don’t feel like they I just feel like up here there still needs a lot of improvements from the people who are still scared.” (Cp12)</i></p> <p><i>“There’s still a lot of work to be done with people here. They need to be well-educated: you’re not going to catch HIV by touching the person, hugging the person, shaking their hand or hanging out with the person. You and I know very well how you’ll catch HIV, how it’s transmitted. So it’s hard, and that’s why I don’t access anything up here. It’s why I go all the way downtown Toronto. Downtown Toronto, I’ve never had a bad experience.” (Cp12)</i></p> <p><i>“And I say that because I am married to a wonderful man who is negative and I don’t see him treating me any differently. I mean, he married me, so that says a lot and he’s still not infected or anything and some people have just such an open mind where they will research and do things just to learn more. But others have a blocked mind and I don’t know what anyone can do about that because they are some educated people, of the ones that I know.” (Cp13)</i></p> <p><i>“Also, if a case comes up and they’re talking about what would happen in that case, how should you respond to this and what should be done, the suggestions that are given and the disgust that is shown by people is quite interesting to observe, actually. It’s very interesting because I say, ‘wow, the things that you don’t know because you’re sitting right next to a person who is infected</i></p>
--	--

	<p><i>by that disease and you don't even know it. You shake my hand and you eat with me, but you have absolutely no idea.' So we've got a very long to go and I'm not sure that it will ever go away because it's been many, many years of observing that there's not much difference unless people are educated and aware. I'm going to breathe air that is going to infect you. It appears to me that they still think that's what could happen."</i> (Cp13)</p> <p><i>"So, when you're not positive and you're sitting and saying all those things and you don't really know who is sitting right next to you, it can be quite painful."</i> (Cp13)</p> <p><i>"I still feel there is so much ignorance and I still feel there's so much blame. That's the part that's sad because people don't know how you got infected, but there's still the question of 'how did you get that?' and other stuff."</i> (Cp13)</p>
Isolation	<p><i>"I am! And I'm out there like: Oh! Another one! And another one! And they slowly come out and around, and then I never see them again for weeks at a time."</i> (Cp01)</p> <p><i>"Even the straight women counsellors at ACDR keep saying that: We have so many men who are gay who are regularly expressing how there's so many other gay men in the Durham area who are lonely, isolated, unhappy."</i> (Cp01)</p> <p><i>"We're not close friends with anyone; I don't think there's a lot of social support... I feel lonely living out here... I feel isolated everywhere we've lived"</i> (Cp02)</p> <p><i>"You know, for me it's no different than living right downtown in the ghetto. We still felt isolated. So I feel exactly the same way."</i> (Cp02)</p> <p><i>"A lot of straight men who were living with HIV who would not come back to this support group because they always thought they were being hit on."</i> (Cp03)</p> <p><i>"I used to come to they used to have a regular support group. But we, the long term survivors, you'd think we'd be mentors to - and we've all taken courses to mentor those who are younger coming in newly diagnosed with HIV, but they don't want to be around us. They don't want to end up like us, its most peculiar. They don't really even want to be identified, and they don't want to share in a support group. When I initially came to my AIDS Service Organization, there was a great support for each other: We</i></p>

	<p><i>cooked together, we did projects together, we expressed ourselves together.” (Cp03)</i></p> <p><i>“And relationships are important to maintain at this stage of your life because they don’t come easily unless you access social engagements, you put yourself out there in the community, and there’s the tendency to want to hold back and just isolate yourself. Either because you don’t think you’re like everybody else, or you’re not of the same health as everybody else, or you’re not as good as everybody else.” (Cp03)</i></p> <p><i>“There’s a support group and it takes different forms. Sometimes their outings are just social. Other times, it’s an instructional video and having some dialogue about it. I don’t feel I can participate in that group because I, I guess I feel that because I’m married I’m defined as a straight person and wouldn’t be welcomed in the group. So maybe I’m self-stigmatizing. I don’t know. That’s been my thought around that particular example.” (Cp04)</i></p> <p><i>“Very much so. There’s times when I want to get together with people and be able to be HIV positive. I don’t use the label openly. If people have asked, or if are curious as to different things that I may have let slip, I’m not secretive about it in that sense, nor do I advertise. But there’s times when I would like to be with a group of people where I can wear that aspect openly, and certainly you can’t I can’t find an outlet for that in Durham region.” (Cp04)</i></p> <p><i>“Well, I mean the diagnosis itself has had an impact on me and my mental health: it’s a blow. But the isolation that we sort of already spoke a bit about socially, and this sort of tiptoeing that you have to do somewhat, yeah.” (Cp04)</i></p> <p><i>“As I say, I think some of it’s me. But some of it is also just the awareness that this is what the funding was intended for, and the funding is such that it creates silos, right? Women is another group that has some energy as far as the funding streams go, and so you see some more focused programming for them. And again, that’s not something I can participate in.” (Cp04)</i></p> <p><i>“When we first moved there, it wasn’t like that though. It was very -- we were shunned; I guess because they thought maybe that we were a gay couple or something like that.” (Cp05)</i></p> <p><i>“I couldn’t even go outside my door. People were throwing eggs at my house. It was bad.” (Cp06)</i></p>
--	--

	<p><i>“It’s not that I had them. I, you know what, just as I was answering that question now, they were my relationships. Wow. I’ve they were my social life. Sitting here now, outside of a service provider, there may be one or two people I could call and say, ‘hey, do you want to go for coffee?’” (Cp10)</i></p> <p><i>“This community here? Exhausted. Exhausted. Imposed upon. Compromised. I don’t feel a part of it. I don’t feel connected to it. I feel like an outsider. Totally.” (Cp10)</i></p> <p><i>“I had an emotional breakdown - I didn’t have, like, a nervous breakdown, but I emotionally, I was starving to unwind because it was just so - I was totally alone.” (Cp10)</i></p> <p><i>“I would say especially when I first came, everything felt so isolating. And it still happens sometimes. Sometimes you just don’t feel you feel like there should be more. Like you should be doing more. Like there should be, I don’t know, like getting out with more positive more, just more. You want to do more. And sometimes you don’t know what to do. Especially in the winters up here, I do start to feel isolated and all closed in and boxed in.” (Cp11)</i></p> <p><i>“I feel a bit alone. I feel a bit like you’re thrown, you know, like an animal you don’t want and leave him in the backyard and just let him stay there. That’s the way I feel, to be honest with you.” (Cp12)</i></p> <p><i>“you feel alone; like the health care you’re looking for is not here” (Cp12)</i></p> <p><i>“The only thing that, to be honest with you, that I find is being alone. I see myself being alone for the rest of my life until I go.” (Cp12)</i></p> <p><i>“Yes, because it’s hard to find someone that’s going to accept you and love you for who you are say, ‘it’s ok, we can protect ourselves this way.’ I’ve come to the conclusion that that’s how it’s going to be for me: alone. Because not everybody is going to take it well or so I already had the experience where I tried to be with someone and I disclosed and I saw their reaction, ‘oh it’s ok’ but the next day you don’t hear from the person ever again and the person pulls away from you. So that’s why I made the decision that I’m just meant to be alone and I’m going to be alone.” (Cp12)</i></p>
--	---

	<p><i>"I can't say much about them because I don't know them personally. Everybody says hello to everybody when you meet them, but I don't know them on a first-name basis, and that's partly, I guess, because of everybody's life. Everybody is seemingly a busy lifestyle here. The only people that I would I know closely, would be like the church go. Close enough to know their first name and go into their homes, but I'm always busy and I come late, so I don't get to know a lot of people around me."</i> (Cp13)</p>
Transportation	<p><i>"It would be very difficult for me. The time to get downtown would probably be extended to two and half to three hours, versus 45 minutes by car. So it would be more difficult, but I don't think I would access the medical services any less. I would still find it important to go, even though it would take triple the time."</i> (Cp01)</p> <p><i>"Yeah, I think I see less medical treatment than if I lived downtown. I lived across the street from my doctor, so I would probably access him more often. I do access medical services a little bit less because it takes so long to get to downtown."</i> (Cp01)</p> <p><i>"It would cause more stress, more difficulty getting there. Perhaps safety for me, myself."</i> (Cp01)</p> <p><i>"TTC stands for Take The Car. I'm just not doing it."</i> (Cp02)</p> <p><i>"And I was hesitant about moving this far away from Toronto. I didn't want to be too far from the hospitals because they keep saving my life. I'm on my third cancer and they keep fixing me."</i> (Cp02)</p> <p><i>"So that was handy for me because I drive, but for everyone else it was difficult, transportation-wise, to get out there."</i> (Cp03)</p> <p><i>"I'm a transit-er. Public transit. So, typically, I'll take the bus. It's not easy taking the bus, to be honest. So living in Oshawa, the Positive Care Clinic is in Whitby, so you have to get into Whitby, and I'm not even sure what bus, if any bus, would get you to the Positive Care Clinic. So I'll generally take a taxi."</i> (Cp04)</p> <p><i>"Oh if I were to go direct, it would probably cost around \$30"</i> (Cp04)</p> <p><i>"Particularly when I was existing exclusively on ODSP support, yeah. I mean it's a very modest income to begin with. So a \$60 taxi is not in the budget at all."</i> (Cp04)</p>

	<p><i>“Well, sure. Unfortunately, the sacrifice is generally your health. You don’t spend the \$60 on a taxi, you don’t go to the appointment, you just sort of hope the issue will resolve on its own and not develop into something more serious.” (Cp04)</i></p> <p><i>“Regarding transit, it is such a huge investment of time trying to travel by transit. If I were driving, I could spend 10-15 minutes travel time. Travelling by transit however, that time swells to an hour or more. If you’re considering urgent, or walk-in services, transit is simply too prohibitive, its sadly easier to shut oneself in, to not travel.” (Cp04)</i></p> <p><i>“You have access to volunteer driver programs, but they like to schedule that in advance. And as you sort of interpreted, my routine HIV appointments were easy to schedule a volunteer driver for, but when going in for a more urgent or immediate health concern... that’s not always falling into a timeframe where the volunteer drivers can be scheduled.” (Cp04)</i></p> <p><i>“Yeah. I shattered a couple of knuckles. A lot of pain. My hand was huge, and I didn’t have any money. I called the ACDR and they told me that they needed two weeks. I said, ‘look, this just happened and I need to go get this checked.’ ‘We can’t help you.’ So I had to wait. I had to wait until my work disability came in before I could go.” (Cp06)</i></p> <p><i>“Spend a lot of money on cabs... To date? Thousands and thousands and thousands and thousands.” (Cp06)</i></p> <p><i>“I have to call the ACDR and we only have one driver for years, now we have three. But we have to give them two weeks’ notice. So, say my cardiologist or my gastroenterologist needs to see my right away, if it’s not two weeks, they wouldn’t even put our name on the list unless we give them two weeks’ notice, which is bull.” (Cp06)</i></p> <p><i>“To see a doctor, to make sure people don’t live so far.” (Cp07)</i></p> <p><i>“Yeah, it is very hard. Very hard.” (Cp07)</i></p> <p><i>“One time, I was late, I was given another date, two weeks ahead and I was feeling so bad and I told her I was late because of the bus, but she said there is no other option, and she pushed me away to come home and to wait for the date that they update.” (Cp07)</i></p>
--	--

	<p><i>“If my appointment’s at, say, ten o’clock, I’ll have to take the bus at 7am... I don’t really know the bus schedules.” (Cp08)</i></p> <p><i>“Transportation is the hardest part here. With just being new to the city, it’s getting used to the bus systems and getting there.” (Cp09)</i></p> <p><i>“A bus doesn’t run from here to my doctor’s in a straight line: I’d have to go downtown and then back uptown. It doesn’t make sense.” (Cp09)</i></p> <p><i>“It’s a fine line between food and transportation. Budgeting food costs and travel has been hard especially when I first moved here. We were behind the ball for about the first three months, trying to get money back rolling again in our favour. We would have to walk down to - we didn’t even know about the ACDR at that time. We would have to walk down to the food bank, grab our food and then walk back, which is not fun going through uptown and downtown. And that happened a few times trying to get food.” (Cp09)</i></p> <p><i>“It’s a - without transportation it’s probably putting a higher risk on my health with my kidneys and walking so far and not eating properly.” (Cp09)</i></p> <p><i>“Oh God! If I didn’t have my car, I wouldn’t go to the half of them. It’s too much work. Public transit? I couldn’t get there and back if I didn’t have a car.” (Cp10)</i></p> <p><i>“I spent \$8,600 in six months driving back and forth to Toronto... There’s times when I’ve had to do without food in order to put gas in the car.” (Cp10)</i></p> <p><i>“It would reduce them because transportation here is not the best. It’s not the best in Toronto either, but it would reduce the amount of go to because, like, getting out to services and appointments using public transit in a city like Toronto isn’t so bad because you’ve got the subway. Out here, it’s a nightmare. I’d be lost without the car.” (Cp10)</i></p> <p><i>“I just know how to get to the subway stations; it’s weird! And that’s it! You have to direct me how to get there, you know, what train to take I would get lost down there. I hated that experience. I hated it, I hated it, I hated it because I’m way out here.” (Cp11)</i></p>
--	--

	<p><i>“Here’s how hard it is for me: I have to take the 407 bus and go to Oshawa, then wait for the 90 to get to the GO station. And then sometimes I would get there and see the train taking off, or sometimes I would be on the bus praying please, please, please because I’ve still got to go and buy my ticket. And it’s so stressful going through all that. And then when I get on the GO Train and get off and go to the TTC and have to take the streetcar, it’s just too much.” (Cp11)</i></p> <p><i>“Like two hours, just to get there – one way!” (Cp11)</i></p> <p><i>“Yes! When you come back, you’re so exhausted from just traveling alone.” (Cp11)</i></p> <p><i>“It’s hard because I don’t drive and I have to rely on transit. Durham transit is a pain if you know it. It’s every half an hour, depending on where you live. For the busses, sometimes you have to transfer to another bus and when the first bus is late, you miss the transfer and have to wait half an hour or more for it to come so I can get to my appointment. So it’s definitely not easy.” (Cp11)</i></p> <p><i>“Oh my God! Exactly, right?! I wish if it were covered by ODSP to just take a taxi, especially if you’re up here. Honestly, I have to find out about that because I know in Toronto they pay for it, but you can’t take a taxi, at least for me, I was not able to do that so I had to use transit.” (Cp11)</i></p> <p><i>“Half the time you’re waiting there and there’s no bus coming. I tried to take the bus downtown, but the bus broke down. So we had to sit down there and wait for another bus to show up. All these things are an inconvenience.” (Cp11)</i></p> <p><i>“And then when you show up late, you’ve got to sit down and continue to wait because the doctors’ are all pissed off at you for not valuing their time, you know? Stuff like that, I hate doing that. I hate showing up late to something. You know that feeling that you get? Jeez. It bugs you and makes you all anxious when you’re late. I hate that feeling.” (Cp11)</i></p> <p><i>“Sometimes it could be a bit much, you know? Just trying to get to where you’ve got to go, especially transportation-wise. Because Oshawa is not like Toronto it’s not every 15 minutes. And sometimes it’s a pain and I get so weak. The last time I had to call my sister from work, I was going to see a gynecologist because I was menstruating for five months straight and my blood count was so low. I always have a low blood count in any case, but I was so</i></p>
--	--

	<p><i>weak I tell you, I couldn't even stand up for very long. And I just couldn't put on my clothes and go there and stand and wait for the bus. I had to call my sister to take me to the appointment. So sometimes it's hard getting to the appointments, especially when you're not driving."</i> (Cp11)</p> <p><i>"It depends. If I don't buy my bus pass, it's more. And if I do, would you believe that two years ago when I started with the bus pass it was \$35 and now it's \$46. And that's the access bus pass and ODSP pays half of it, and I pay the \$46, and they pay the government the rest because the real bus pass, I think, is something like \$90 or more."</i> (Cp11)</p> <p><i>"So for me, it's a little bit hard traveling over there, the wait times, the travel times and the traffic, and then waiting to come back home. Why do I need to go all the way down there? Why can't there be better, easier way for me to access a doctor that is a specialist up here? That I haven't been able to find up here."</i> (Cp12)</p> <p><i>"I have to call a day in advance and they pick me up at my appointment and they leave me at my appointment and I have to call them to pick me up when I'm finished. Sometimes it takes about an hour's wait downtown for a cab to come and pick me up. It's frustrating."</i> (Cp12)</p> <p><i>"Like, for me, living here it's hard. Getting around, I wish I could just get on the bus"</i> (Cp12)</p> <p><i>"I used to drive, but I'm not allowed to drive anymore because of the medication that I'm on, right? It makes me drowsy and dizzy, so I could put my life in danger and put others in danger."</i> (Cp12)</p> <p><i>"You feel the pinch because you have to make all these appointments and keep going downtown and paying the transit here and there as well."</i> (Cp13)</p> <p><i>"I would say, once every three months, because it's not the only place that I go all my doctors are downtown"</i> (Cp13)</p>
Multiple, chronic health conditions	<p><i>"And he has his medical appointments for cancer stuff and stuff like that."</i> (Cp01)</p> <p><i>"I have all kinds of health problems... Yes, it's my third [cancer]."</i> (Cp02)</p>

	<p><i>“This, around here, is called lipodystrophy, which is a relocation of the fats of your body and a humpback and, you know, around here it accumulates, and the joints became a factor because that’s like, arthritis, and I’m pretty sure they’ve diagnosed me with osteoarthritis. And I have trouble moving now with my lower back, walking great distances or standing for a long time. And I’ve also developed diabetes, type 2” (Cp03)</i></p> <p><i>“Yeah, in your older age, having served a long time living with HIV, HIV doesn’t become the primary health issue, it’s other things that begin to crop up and I developed problems with my joints” (Cp03)</i></p> <p><i>“I suffer from chronic back pain, degenerative disk, osteoporosis, 70 per cent. Osteoporosis throughout the body. So, I’m a 55-year old man but I’m in a 78-year old’s body. Very brittle, so I’ve got to be very careful, things like that. I suffer from depression. Optician for my eyes, a urologist - I have urinary problems” (Cp05)</i></p> <p><i>“I’ve had three strokes. I have stomach problems – I have all kinds of problems. I have degenerative bone disease and I have osteoporosis really bad. I’ve got Crohn’s. I have a-fib. I have a stent in, and they’re talking about now giving me a pacemaker. I’m falling apart. I had cancer.” (Cp06)</i></p> <p><i>“Living with schizophrenia... Well, in my life, like I said I’m a recovering drug addict.” (Cp08)</i></p> <p><i>“I have a lot of other issues besides HIV because of HIV. It’s the first time I’ve been told my kidneys shut down or renal failure is caused by HIV.” (Cp09)</i></p> <p><i>“I’m on disability. I’ve lived in chronic pain for eight, nine years.” (Cp10)</i></p> <p><i>“Deal with it. Nothing. That’s why I’m happy to be getting a psychiatrist because I need someone to talk to about, you know? I have a dermatologist and an endocrinologist and another one that I can’t remember. I have different ones for different stuff because different things come up.” (Cp11)</i></p> <p><i>“My anxiety and depression also developed from the diagnosis in 2008. And I have cancer also too. So I was diagnosed with both in the same year at the same time.” (Cp12)</i></p>
--	---

Aging with HIV	<p><i>“This face disfigurement now, it’s one of the conditions you get as a long time survivor of HIV. And it’s sometimes difficult to deal with because it’s not an issue for you because you live with it, but for everybody else who comes into contact with you, they wonder why.” (Cp03)</i></p> <p><i>“I just had an experience before I came here, in fact. I live in a 24-unit building, and this gentleman came out who lives next door to me he’s joking, I know he was I was coming down the rear steps to pick up my car, and he saw me taking one step at a time. But slowly going down and accessing the steps, there’s 16 at the back eight and eight and then I was on the lower eight and he just said, ‘Well those of you who have more poundage or more pounds, I’m hoping that that’s secure enough for you to hang on to.’” (Cp03)</i></p> <p><i>“Yeah, I think so. They just figure you’re normal now and you’re going through the same symptoms that everyone else is going through, when I probably wouldn’t be in this situation if I hadn’t got diagnosed with HIV 26 years ago! So we don’t know what status state I would be in, living and aging, as I regularly would without living with HIV. They don’t understand that there’s a correlation between what genes you have in your body that is inherited from your family, as well as what you could develop later in your life.” (Cp03)</i></p> <p><i>“But we’re getting - I’m getting issues earlier. The stats are becoming more clear that a long-term surviving person with HIV is aging earlier and getting other symptoms from other diseases a little sooner than everybody else who say develops cancer or develops” (Cp03)</i></p> <p><i>“But you have to check on all these things it’s an ongoing thing. And you don’t know whether or not it’s just old age or something related to HIV or something related to whatever else you have.”(Cp03)</i></p> <p><i>“And the difficulty today is, when I go, they’re looking at other symptoms where normal people are aging they’re not looking at the HIV anymore because it’s like we haven’t cured you, but we’ve got it in a status now that’s not really the issue. Whereas now other health issues are occurring because of your aging, and I don’t think that’s correct because one doesn’t live without the other.” (Cp03)</i></p> <p><i>“I told them that the medication is what’s doing it to my teeth. I was on pretty strong medication when it first came out and it</i></p>
----------------	--

	<p><i>rotted the back of my teeth - the front are fine, but I had no backs to them. I would say it was from some medications that I was on. I was on medication for quite a few years that caused me osteoporosis, which was the drug Truvada and nobody knew it at the time, but it brought on my osteoporosis.” (Cp05)</i></p> <p><i>“HIV is something where you can feel fine for a whole, I would say six months, and then suddenly something happens and you get really, really sick.” (Cp11)</i></p> <p><i>“But the medications that I’m on, they make me feel very gross and bad. There’s days that I can tell you that I don’t even come out of my room; I sleep all day because the medications make me drowsy, tired, I vomit or I just don’t feel like myself, dizzy, sometimes I can’t even walk.” (Cp12)</i></p> <p><i>“And I had trouble with medication to begin with, so they kept changing that. Recently, I’ve had it changed again.” (Cp13)</i></p>
Health care service delivery	<p><i>“Here in Durham, when I go to see my diabetic doctor, she doesn’t share any information with my family doctor. She doesn’t share any information with my HIV doctor. I’ll go to another doctor in Durham, they don’t share their information with the diabetic doctor. There’s no sharing of information in Durham. So screw it! Why would I give blood twice when I can go downtown and give it once? Why would I visit four different doctors when I can go down there and, at least, they can share the info and talk to each other.” (Cp01)</i></p> <p><i>“The reason why I go downtown for medical, the network is much bigger. I can go to my HIV doctor and he has referred me to a diabetic doctor. He has referred me to a neurologist because I have problems with my feet. He has referred me to my kidney doctor” (Cp01)</i></p> <p><i>“He wouldn’t give my flu shot - this latest pharmacist, because he was worried that nobody was monitoring my conditions after he would have administered this flu shot... Every time I go, they want to go through my list with me to confirm this is what you need, this is what you’re taking, is this current, have you had a -- are you maintaining a regular schedule with your family doctor and your specialist, are you getting your blood work done, are you maintaining this healthy liaison with the health services...” (Cp03)</i></p> <p><i>“Because even I go for my diabetes, they say they know, but they really don’t equate how diabetes I got diabetes after I was</i></p>

	<p><i>infected with HIV, and it took a long time to develop. I knew I had it even a couple of years before they diagnosed what it was. And I went to tell them, they don't like you to outguess them and that you know your body better than they do."</i> (Cp03)</p> <p><i>"And you have to think of distance how close are you to accessing these services, these meds, these doctors, everything. You have to consider all that if you're going to make a move, and a move late in your life is difficult"</i> (Cp03)</p> <p><i>"He's always been my doctor since I've been here. But I know his limitations, and he has a large clientele, so he doesn't make he would rather and does he takes out his little pad and writes you a prescription immediately... Family doctors are still living in the dark ages."</i> (Cp03)</p> <p><i>"Even where to get their meds and even where to stay in contact with the hospital system, they really have trouble with the long distance; it's not easily accessible."</i> (Cp03)</p> <p><i>"And my current family doctor, we could quote what he said, 'doctors don't seem to want to take on sick patients'"</i> (Cp04)</p> <p><i>"When I was initially enrolled in the nurse practitioner program, I think that model is very much one of outsourcing. If that makes sense? So, they can do some things there, but everything has to be signed off by a doctor who isn't always present. And, who, coincidentally, in the year and half that I was in that program, I never once saw."</i> (Cp04)</p> <p><i>"Sometimes I'll be given a pill, but I shouldn't be taking it because I'm taking another pill and it'll take away the strength of that pill and that's happened."</i> (Cp05)</p> <p><i>"Yes, the Positive Care Clinic and my family physician are consistently sending stuff back and forth. If my doctor wants to me on something, he'll send a note to my psychiatrist, for example, for my depression pills and so on."</i> (Cp05)</p> <p><i>"I went to my [general practitioner], he sent me to Lakeridge, Lakeridge kicked me back the Positive Care Clinic, the Positive Care Clinic back to my [general practitioner], and this went on and on and on. It's still going on!"</i> (Cp06)</p>
--	--

	<p><i>“Dr. [name withheld] wrote the script, and I said, ‘where do I get this done?’ and she told me, ‘Go see your [general practitioner].’ She wouldn’t even look it up, it was pathetic” (Cp06).</i></p> <p><i>“Let’s see Lakeridge, Bowmanville, Peterborough, Lakeridge, Whitby, Ajax, and some other place are all connected now. So they can log in and be connected to eight or 10 different hospitals now.” (Cp06)</i></p> <p><i>“Lakeridge it is not good because you go, you stay, it takes a long, because you don’t know anybody there. Yeah, you take long to get to the doctor and they can’t give you medicines.” (Cp07)</i></p> <p><i>“Sometimes they do better to you than in Lakeridge because in Lakeridge you wait in emergency and you feel so bad. You have pain, but if nobody takes you around, it is so hard.” (Cp07)</i></p> <p><i>“I guess most of the time it’s going over history that you repeat a lot.” (Cp09)</i></p> <p><i>“Whereas going to St. Catherine’s, you’re always thinking, ‘what’s next? What idiot doctor am I going to get?’” (Cp09)</i></p> <p><i>“I discovered through trial and error that if I didn’t have you connected to this one or that one and that one connected to this one or that one, I was going to spend a long time waiting for one thing to happen. A year. Whereas if everyone was connected, I could have it happen within six weeks.” (Cp10)</i></p> <p><i>“I know a lot of friends that prefer to go to Toronto for their care. They prefer it because they think they’ll get to see better specialists, and everybody’s experience is different. But a lot of them prefer to go to Toronto to seek care.” (Cp11)</i></p> <p><i>“So it takes a while to get a referral for any - I find it more - and another thing is family doctors. It took me a while to get a family doctor because most of the doctors, especially if you have to walk into any urgent care, most of them don’t even know what is going on with the medications for HIV I know more than them, so it’s hard having a family doctor that knows nothing. And then you have to explain everything to him. It’s hard getting somebody who doesn’t know anything. If I’m on a whole lot of other medications, and you have to supply me with something, I’m going to be scared that there could be some interaction.” (Cp11)</i></p>
--	--

	<p><i>“if you have to walk into any urgent care, most of them don’t even know what is going on with the medications for HIV -- I know more than them -- so it’s hard having a family doctor that knows nothing. And then you have to explain everything to him. It’s hard getting somebody who doesn’t know anything.” (Cp11)</i></p> <p><i>“But, how I feel when I know he doesn’t know a whole lot about it, not confident. It makes me worried. And the first time it happened, it was so surprising that a lot of them they don’t a whole lot.” (Cp11)</i></p> <p><i>“It depends. My specialist wasn’t a lot. It was once every three or six months. It depends if we were trying new meds or something like that. But for the psychiatrist, that was once every month.” (Cp11)</i></p> <p><i>“But I’ve noticed that accessing mental health is completely different. It takes longer. I’ve been looking for a psychiatrist for about a year now” (Cp11)</i></p>
Social care service delivery	<p><i>“There was this one point when I thought the agency would join together with the Positive Care clinic in one location, where all your services could be together and that’s not yet happened. That was a goal of one of our previous CEOs. It’s difficult.” (Cp03)</i></p> <p><i>“So, moving, for example, from Toronto to Oshawa, it was unclear if I could get any sort of any relocation support. And querying my caseworker in Toronto, they said, ‘you’ll have to speak to your new caseworker in the new area.’ Well, you don’t know who that is. So there’s no transparency whatsoever. So navigating the ODSP system, in particular, is very, very challenging.” (Cp04)</i></p> <p><i>“Yes. So I find a lot of the social services are directed at that population, and that’s great. I’m not saying that those should disappear or be less. But they do exclude the straight population.” (Cp04)</i></p> <p><i>“It was the social services that were really, really difficult to navigate, and they’re an ongoing challenge here. I moved three months ago. When I call them, they won’t acknowledge that they’ve received my change of address form, and yet they send my ODSP statements and my dental and health benefit card to my old address, but they’ve determined that I owe them money because they’ve overpaid, but they manage to send that to the right address. And they still don’t acknowledge that they haven’t</i></p>

	<p><i>received my change of address, right? So, it's a frustrating system. Social supports: huge, huge problem."</i> (Cp04)</p> <p><i>"I was in Durham region for two years before I knew I could get an accessibility bus pass. Some of that responsibility lies on me, but some of it lies on the service providers, right? They know when I'm going to an appointment for the first time, for example to the Positive Care Clinic. 'How are you getting here?' 'Oh, I'll be coming by transit or by GO Train or whatever' Then they know that I don't drive. There's where you'd think that there'd be a quick, 'Oh. Do you know that you can get an accessibility bus pass on ODSP?' Anyway, so some of that information is not easy to access or find out about. My own experience, I think, is different by the fact that I had some navigation before coming to Oshawa. So I can't imagine what it's like in Oshawa, or Durham region rather, if/when you're initially diagnosed because that sort of one-year window of time as you try to navigate the system, it's incredibly difficult."</i> (Cp04)</p> <p><i>"It was the social services that were really, really difficult to navigate, and they're an ongoing challenge here. I moved three months ago. When I call them, they won't acknowledge that they've received my change of address form, and yet they send my ODSP statements and my dental and health benefit card to my old address, but they've determined that I owe them money because they've overpaid, but they manage to send that to the right address. And they still don't acknowledge that they haven't received my change of address, right? So, it's a frustrating system. Social supports: huge, huge problem."</i> (Cp04)</p> <p><i>"When I look at my own personal journey, a lot of the resources that I made use of or was made aware of, don't exist in Durham region. So I can't imagine what the experience for people who are diagnosed in Durham region must be like. It would be like being in a bumper car and your vehicle doesn't drive: you're just being hit by everything and thrown all over the place."</i> (Cp04)</p> <p><i>"They're designed to say no. See, the Act is the legislative body, whereas the people that are running it, most of which are, to-date, caseworkers instead of social workers and midlevel bureaucrats that are operating under management pieces that are structured like an insurance company, for example. We have this policy and this is what we're offering, but when you come looking for it, we say no. We're going to make you work to get it. And we're not just going to make you, we're going to make you WORK! Instead of one hoop, there's 20. And we will not cut off three at a time, we'll</i></p>
--	---

	<p><i>cut off one, one, one. And I learned that the hard way in the first couple of appeals I made. So now when I go at it, I'm covered for six, seven, eight hoops in one shot, in one letter. I know the key phrases and words to put in and I communicate with my specialist and they put them in for me.” (Cp10)</i></p> <p><i>“they’ll say they won’t do it based on a referral; they have to know that it’s been prescribed. So then I have to get a prescription, and then they’ll say that they need to know if it’s necessary. And then they’ll come back saying that it’s prescribed and necessary, but is it essential? And then you’ll come back showing that it’s essential and they’ll say no, is it essential based on the fact that you’re HIV positive? And most people by the time they get to the third letter just give up and walk away.” (Cp10)</i></p> <p><i>“What I in order to keep ODSP happy, I had to keep things current. I can’t let something go for six to eight months because after that length of time, the backlog means that it’s going to be even longer to get it revised and updated.” (Cp10)</i></p> <p><i>“But the thing is, I find it really restrictive and it’s hard sometimes trying to access the simplest of things - and they’re the things that you would think they would care more about - no! They’re cut. I was going through - I’m still going through - my immigration stuff, and they don’t help with any of that. Anything that you have to pay for, although you’re on ODSP, there’s no one to help you. You have to come up with the money to pay for it. There’s no help with that. Every time you call, ‘oh no, we don’t do that. No, we don’t pay for that.’ There’s a whole lot of stuff that you would think, you know, I mean, I’m on a fixed income and its hard trying to find \$600 to pay for this and that when my income alone is \$1,200.” (Cp11)</i></p> <p><i>“Public transit, I really don’t take it because I the reason why I’m taking cabs is because I was taking public transit before on the TTC and I passed out and woke up in the hospital. So I don’t know what happened. The doctor who saw me there said I can’t really be alone because of the medications that I’m on and someone should accompany me just in case. Because the medication that I was on before was making me very dizzy and tired, very disoriented. That doctor wrote a letter to my disability worker because she wanted to know why I needed a cab when I should be capable of taking the TTC. He had to explain why.” (Cp12)</i></p>
--	---

	<p><i>“No, it’s just a worker that I’m assigned to at disability. So if I need anything, or if anything has changed, or if I’m looking for work, I have to call her. Sometimes, it’s hard to access her because sometimes she’s really hard to get a hold of. So you feel like, how do you go about doing the things you want to do? How do you go about getting the services that you need, if you don’t have that great support from the workers? Like, those workers are supposed to be there working for you and helping you the best way they can. So sometimes it’s frustrating: instead of helping you, they make you more frustrated and it gets your more sick.” (Cp12)</i></p> <p><i>“It’s a taxi company that I have to look for by myself, which is another thing that I found to be a little bit hard when I first came to this area. The worker told me that I had to look for a company. I used to live in Mississauga and they used to do everything; disability knew which cab company they were going to work with. But here, I had to look for the cab company and I had to keep calling and calling and then call her and tell her the name of the cab company and then should be tell me that they don’t work with that cab company or this cab company. And I’m like what do I do? Who do I call? Finally I got fed up, but she -- I found a cab company that would take me.” (Cp12)</i></p>
--	--

References

- Adams, C., & van Manen, M. (2008). Phenomenology. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 615-620). doi:10.4135/9781412963909.n317
- Aday, L. A., & Andersen, R. (1974). A framework for the study of access to medical care. *Health Services Research*, 9(3), 208-220.
- Adorno, G., Fields, N., Cronley, C., Parekh, R., & Magruder, K. (2016). Ageing in a low-density urban city: Transportation mobility as a social equity issue. *Ageing and Society*, 1-25. doi:10.1017/S0144686x16000994.
- AIDS Committee of Durham Region. (2016). *About us* [Internet]. Retrieved from <http://www.aidsdurham.com/index.html>
- Akselrod, H., Grau, L. E., Barbour, R., & Heimer, R. (2014). Seroprevalence of HIV, hepatitis B virus, and HCV among injection drug users in Connecticut: Understanding infection and coinfection risks in a nonurban population. *American Journal of Public Health*, 104(9), 1713-1721. doi:10.2105/AJPH.2013.301357
- Andrews, F. J. (2010). Parental perceptions of residential location: Impacts on children's health. *Health and Place*, 16(2), 252-258. doi:10.1016/j.healthplace.2009.10.006
- Bardet, J-D., Vo, T-H., Bedouch, P., & Allenet, B. (2015). Physician and community pharmacists collaboration in primary care: A review of specific models. *Research in Social and Administrative Pharmacy*, 11, 602-622. doi:10.1016/j.sapharm.2014.12.03
- Berg, R. C., & Ross, M. W. (2014). The second closet: A qualitative study of HIV stigma among seropositive gay men in a southern US city. *International Journal of Sexual Health*, 26(3), 186-199. doi:10.1080/19317611.2013.853720
- Boeri, M. W., & Tyndall, B. D. (2012). A contextual comparison of risk behaviors among older adult drug users and harm reduction in suburban versus inner-city social environments. *Journal of Applied Social Science*, 6(1), 72-91.
- Boniface, S., Scantelbury, R., Watkins, S. J., & Mindell, J. S. (2015). Health implications of transport: Evidence of effects of transport on social interactions. *Journal of Transport & Health*, 2(3), 441-446. doi:10.1016/j.jth.2015.05.005
- Boulden, W. T. (2001). Gay men living in a rural environment. *Journal of Gay & Lesbian Social Services: Issues in Practice, Policy & Research*, 12(3-4), 63-75. doi:10.1300/J041v13n01_06.

- Bourgeault, I., Dingwall, R., & de Vries, R. (2010). Introduction. In I. Bourgeault, R. Dingwall, & R. de Vries (Eds.), *The SAGE handbook of qualitative methods in health research* (pp. 1-16). Thousand Oaks, CA: SAGE Publications Inc.
- Bowling, A. (2014). *Research methods in health: Investigating health and health services* (4th ed.). Berkshire, UK: McGraw Hill Education.
- Brooks, J. T., Buchacz, K., Gebo, K. A., & Mermin, J. (2012). HIV infection and older Americans: The public health perspective. *American Journal of Public Health*, 102(8), 1516-1526. doi:10.2105/AJPH.2012.300844
- Bruggmann, P., & Grebely, J. (2015). Prevention, treatment and care of hepatitis C virus infection among people who inject drugs. *International Journal of Drug Policy*, 26 Suppl 1, S22-S26. doi:10.1016/j.drugpo.2014.08.014
- Carman, M., Grierson, J., Pitts, M., Hurley, M., & Power, J. (2010). Trends in the location of the HIV-positive population in Australia: Implications for access to healthcare services and delivery. *Sexual Health*, 7(2), 154-158. doi:10.1071/sh09063
- Carter, C. I., & MacPherson, D. (2013). *Getting to tomorrow: A report on Canadian drug policy*. Vancouver, BC: Canadian Drug Policy Coalition. Retrieved from http://drugpolicy.ca/report/CDPC2013_en.pdf
- Chambers, L. A., Rueda, S., Baker, D. N., Wilson, M. G., Deutsch, R., Raeifar, E., . . . The Stigma Review Team. (2015). Stigma, HIV and health: A qualitative synthesis. *BMC Public Health*, 15, 848. doi:10.1186/s12889-015-2197-0
- Cooper, V., Clatworthy, J., Youssef, E., Llewellyn, C., Miners, A., Lagarde, M., . . . Sabin, C. (2016). Which aspects of health care are most valued by people living with HIV in high-income countries? A systematic review. *BMC Health Services Research*, 16(1), 677. doi:10.1186/s12913-016-1914-4
- Cope, R., Arcebedo, R., & Trustman, N. (2015). Evaluating the effects of an interdisciplinary practice model with pharmacist collaboration on HIV patient co-morbidities. *AIDS Patient Care and STDs*, 29(8), 445-453. doi:10.1089/apc.2015.0018
- Cramer, R. J., Colbourn, S. L., Gemberling, T. M., Graham, J., & Stroud, C. H. (2015). Substance-related coping, HIV-related factors, and mental health among an HIV-positive sexual minority community sample. *AIDS Care*, 27(9), 1063-1068. doi:10.1080/09540121.2015.1024097
- Cunningham, W. E., Andersen, R. M., Katz, M. H., Stein, M. D., Turner, B. J., Crystal, S., . . . Shapiro, M. F. (1999). The impact of competing subsistence needs and barriers on access to medical care for persons with Human Immunodeficiency

- Virus receiving care in the United States. *Medical Care*, 37(12), 1270-1281. doi:10.1097/00005650-199912000-00010
- Dasgupta, S., Kramer, M. R., Rosenberg, E. S., Sanchez, T. H., & Sullivan, P. S. (2016). Development of a comprehensive measure of spatial access to HIV provider services, with application to Atlanta, Georgia. *Springerplus*, 5(1), 1-12. doi:10.1186/s40064-016-2515-8
- Deber, R. B., Gamble, B., & Mah, C. L. (2010). Canada: Variations on a common theme. *Italian Journal of Public Health*, 7(4), 336-343.
- Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44(1), 131-142. doi:10.1016/j.ijnurstu.11.026
- Draus, P., Roddy, J., & Greenwald, M. (2012). Heroin mismatch in the motor city: Addiction, segregation, and the geography of opportunity. *Journal of Ethnicity in Substance Abuse*, 11, 149-173. doi:10.1080/15332640.2012.675246
- Dugdale, C., Zaller, N., Bratberg, J., Berk, W., & Flanigan, T. (2014). Missed opportunities for HIV screening in pharmacies and retail clinics. *Journal of Managed Care Pharmacy*, 20(4), 339-345.
- Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV stigma mechanisms and well-being among PLWH: A test of the HIV stigma framework. *AIDS and Behavior*, 17(5), 1785-1795. doi:10.1007/s10461-013-0437-9
- Earnshaw, V. A., Smith, L. R., Cunningham, C. O., & Copenhaver, M. M. (2015). Intersectionality of internalized HIV stigma and internalized substance use stigma: Implications for depressive symptoms. *Journal of Health Psychology*, 20(8), 1083-1089. doi:10.1177/1359105313507964
- Eberhart, M. G., Voytek, C. D., Hillier, A., Metzger, D. S., Blank, M. B., & Brady, K. A. (2014). Travel distance to HIV medical care: A geographic analysis of weighted survey data from the medical monitoring project in Philadelphia, PA. *AIDS and Behavior*, 18(4), 776-782. doi:10.1007/s10461-013-0597-7
- Eberhart, M. G., Share, A. M., Shpaner, M., & Brady, K. A. (2015). Comparison of geographic methods to assess travel patterns of persons diagnosed with HIV in Philadelphia: How close is enough? *Journal of Biomedical Informatics*, 53, 93-99. doi:10.1016/j.jbi.2014.09.005
- Edwards, J., Palmer, G., Osbourne, N., & Scambler, S. (2013). Why individuals with HIV or diabetes do not disclose their medical history to the dentist: A qualitative analysis. *British Dental Journal*, 215(6), 5. doi:10.1038/sj.bdj.2013.881

- Felland, L. E., Lauer, J. R., & Cunningham, P. J. (2009). Suburban poverty and the health care safety net. *Research Brief*, (13), 1.
- Fieldberg, G., Vipond, R., & Bryant, T. (2010). Cracks in the foundation: The origins and development of the Canadian and American health care systems (pp. 267-285). In T. Bryant, D. Raphael, & M. Rioux (Eds). *Staying alive: Critical perspectives on health, illness and health care* (2nd ed.). Toronto, ON: Canadian Scholars' Press Inc.
- Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, 41(1), 50-67.
- Forsyth, A. (2012). Defining Suburbs. *Journal of Planning Literature*, 27(3), 270-281. doi:10.1177/0885412212448101
- Frumkin, H. (2002). Urban sprawl and public health. *Public Health Reports*, 117(3), 201-214.
- Gagnon, M. (2015). Re-thinking HIV-related stigma in health care settings: A qualitative study. *Journal of the Association of Nurses in AIDS Care*, 26(6), 703-719. doi:10.1016/j.jana.2015.07.005
- Gentry, C. K., Parker, R. P., Ketel, C., Rosenbloom, S. T., Crutcher, T. D., Scott, A. W., ... Pilon, B. A. (2016). Integration of clinical pharmacist services into an underserved primary care clinic utilizing an interprofessional collaborative practice model. *Journal of Health Care for the Poor and Underserved*, 27(1), 1-7. doi:10.1353/hpu.2016.0005
- Gergen, K. J., & Gergen, M. M. (2008). Social constructionism. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 817-821). doi:10.4135/9781412963909.n426
- Giacomini, M. (2010). Theory matters in qualitative health research. In I. Bourgeault, R. Dingwall, & R. de Vries (Eds.), *The SAGE handbook of qualitative methods in health research* (pp. 125-156). Thousand Oaks, CA: SAGE Publications Inc.
- Given, L. M., & Saumure, K. (2008). Trustworthiness. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 896-897). doi:10.4135/9781412963909.n470
- Google. (2016a). *Google for work help – security* [Internet]. Retrieved from <https://support.google.com/work/answer/6056693>

- Google. (2016b). *Google for work help – compliance* [Internet]. Retrieved from https://support.google.com/work/answer/6056694?hl=en&ref_topic=6055719
- Google. (2016c). *Google for work help – privacy* [Internet]. Retrieved from https://support.google.com/work/answer/6056650?hl=en&ref_topic=6055719
- Google. (2016d). *Google for work help – reliability* [Internet]. Retrieved from https://support.google.com/work/answer/6056635?hl=en&ref_topic=6055719
- Gonzalez, A., Miller, C. T., Solomon, S. E., Bunn, J. Y., & Cassidy, D. G. (2009). Size matters: Community size, HIV stigma, & gender differences. *AIDS and Behavior*, 13(6), 1205-1212. doi:10.1007/s10461-008-9465-2
- Gordon, D. L. A., & Janzen, M. (2013). Suburban nation? Estimating the size of Canada's suburban population. *Journal of Architectural and Planning Research*, 30(3), 197-220.
- Gordon, D. L. A., & Shirokoff, I. (2014). Suburban nation? Population growth in Canadian suburbs, 2006-2011 [Monograph]. *Journal of Architectural and Planning Research*, 30(3), 197-220. Retrieved from <http://www.canadianurbanism.ca/wp-content/uploads/2014/07/CanU%20WP1%20Suburban%20Nation%202006-2011%20Text%20and%20Atlas%20comp.pdf>
- Government of Ontario. (2016). *Health services: What's covered by OHIP?* [Internet]. Retrieved from <http://www.health.gov.on.ca/en/public/publications/ohip/services.aspx>
- Green, K. E., & Feinstein, B. A. (2012). Substance use in lesbian, gay, and bisexual populations: An update on empirical research and implications for treatment. *Psychology of Addictive Behaviors*, 26(2), 265-278. doi:10.1037/a0025424
- Gregory, P. A. M., & Austin, Z. (2016). Trust in interprofessional collaboration: Perspectives of pharmacists and physicians. *Canadian Pharmacists Journal*, 149, 236-245. doi:10.1177/1715163516647749
- Groft, J. N., & Robinson Vollman, A. (2007). Seeking serenity: Living with HIV/AIDS in rural Western Canada. *Rural and Remote Health*, 7(677), 2.
- Haack, S. (2008). Engaging pharmacy students with diverse patient populations to improve cultural competence. *American Journal of Pharmaceutical Education*, 72(5), Article 124.
- Hancock, T. (2000). Healthy communities must also be sustainable communities. *Public Health Reports*, 115(2/3), 151-156.

- Hancock, T. (2011). Health promotion in Canada: 25 years of unfulfilled promise. *Health Promotion International*, 26(S2), ii263-ii267. doi:10.1093/heapro/dar061
- Heckman, T. G., Somlai, A. M., Peters, J., Walker, J., Otto-Salaj, L., Galdabini, C. A., & Kelly, J. A. (1998). Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care*, 10(3), 365-375. doi:10.1080/713612410
- Heimer, R., Barbour, R., Palacios, W. R., Nichols, L. G., & Grau, L. E. (2014). Associations between injection risk and community disadvantage among suburban injection drug users in southwestern Connecticut, USA. *AIDS and Behavior*, 18(3), 452-463. doi:10.1007/s10461-013-0572-3
- Holtzman, S., Landis, L., Walsh, Z., Puterman, E., Roberts, D., & Saya-Moore, K. (2016). Predictors of HIV testing among men who have sex with men: A focus on men living outside major urban centres in Canada. *AIDS Care*, 28(6), 705-711. doi:10.1080/09540121.2016.1164288.
- Hubach, R. D., Dodge, B., Li, M. J., Schick, V., Herbenick, D., Ramos, W. D., . . . Reece, M. (2015). Loneliness, HIV-related stigma, and condom use among a predominantly rural sample of HIV-positive men who have sex with men (MSM). *AIDS Education and Prevention*, 27(1), 72-83.
- James, N. (2008). Authenticity. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 45-46). doi:10.4135/9781412963909.n26
- Jeste, D. V., Blazer, D. G., Buckwalter, K. C., Cassidy, K. L. K., Fishman, L., Gwyther, L. P., . . . Vega, W. A. (2016). Age-friendly communities initiative: Public health approach to promoting successful aging. *The American Journal of Geriatric Psychiatry*, 24(12), 1158-1170. doi:10.1016/j.jagp.2016.07.021
- Jones, D., Carroll, L., & Frank, L. (2011). After-hours care in suburban Canada: Influencing emergency department utilization. *Journal of Primary Care & Community Health*, 2(4), 250-254. doi:10.1177/2150131911408431
- Kaukinen, C., & Fulcher, C. (2006). Mapping the social demography and location of HIV services across Toronto neighbourhoods. *Health & Social Care in the Community*, 14(1), 37-48. doi:10.1111/j.1365-2524.2005.00595.x
- Kelly, S. E. (2010). Qualitative interviewing techniques and styles. In I. Bourgeault, R. Dingwall, & R. de Vries (Eds.), *The SAGE handbook of qualitative methods in health research* (pp. 307-326). Thousand Oaks, CA: SAGE Publications Inc.
- Kempf, M. C., McLeod, J., Boehme, A. K., Walcott, M. W., Wright, L., Seal, P., . . . Moneyham, L. (2010). A qualitative study of the barriers and facilitators to retention-in-care among HIV-positive women in the rural southeastern United

- States: Implications for targeted interventions. *AIDS Patient Care and STDs*, 24(8), 515-520. doi:10.1089/apc.2010.0065
- Kendall, C. E., Wong, J., Taljaard, M., Glazier, R. H., Hogg, W., Younger, J., & Manuel, D. G. (2015). A cross-sectional, population-based study of HIV physicians and outpatient health care use by people with HIV in Ontario. *BMC Health Services Research*, 15, 63. doi:10.1186/s12913-015-0723-5
- Klein, S. J., Karchner, W. D., & O'Connell, D. A. (2002). Interventions to prevent HIV-related stigma and discrimination: Findings and recommendations for public health practice. *Journal of Public Health Management and Practice*, 8(6), 44-53.
- Kralj, B. (2009). *Measuring rurality – RIO2008_BASIC: Methodology and results*. Toronto, ON: Ontario Medical Association (OMA) Economics Department. Retrieved from <https://www.oma.org/Resources/Documents/2008RIO-FullTechnicalPaper.pdf>
- Kuyper, L. M., Hogg, R. S., Montaner, J. S. G., Schechter, M. T., & Wood, E. (2004). The cost of inaction on HIV transmission among injection drug users and the potential for effective interventions. *Journal of Urban Health*, 81(4), 655-660. doi:10.1093/jurban/jth148
- Lampkin, D., Crawley, A., Lopez, T. P., Mejia, C. M., Yuen, W., & Levy, V. (2016). Reaching suburban men who have sex with men for STD and HIV services through online social networking outreach: A public health approach. *Journal of Acquired Immune Deficiency Syndromes*, 72(1), 73-78.
- Lamonica, A., & Boeri, M. (2015). Risk behaviors among suburban women who use methamphetamine: Social harms and social solutions. *Journal of Applied Social Science*, 9(2), 98-114. doi:10.1177/1936724414525953
- Lankenau, S. E., Teti, M., Silva, K., Jackson Bloom, J., Harocopos, A., & Treese, M. (2012). Initiation into prescription opioid misuse amongst young injection drug users. *International Journal on Drug Policy*, 23(1), 37-44. doi:10.1016/j.drugpo.2011.05.014
- Laschinger, S. J., Van Manen, L., Stevenson, T., & Fothergill-Bourbonnais, F. (2005). Health care providers' and patients' perspectives on care in HIV ambulatory clinics across Ontario. *Journal of the Association of Nurses in AIDS Care*, 16(1), 37-48.
- Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2(3), 3.

- Lincoln, Y. S., & Guba, E. G. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.) (pp. 163-188). Retrieved from https://sabinemendesmoura.files.wordpress.com/2014/11/gubaelincoln_novo.pdf
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363-385.
- Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science & Medicine*, 71(12), 2150-2161.
- Lofters, A., Guilcher, S., Maulkhan, N., Milligan, J., & Lee, J. (2016). Patients living with disabilities: The need for high-quality primary care. *Canadian Family Physician*, 62, e457-e464.
- Logie, C. H., James, L., Tharao, W., & Loufty, M. R. (2011). HIV, gender, race, sexual orientation, and sex work: A qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. *PLoS Medicine*, 8(11), e1001124. doi:10.1371/journal.pmed.1001124
- Loutfy, M. R., Logie, C. H., Zhang, Y., Blitz, S. L., Margolese, S. L., Tharao, W. E., . . . Raboud, J. M. (2012). Gender and ethnicity differences in HIV-related stigma experienced by people living with HIV in Ontario, Canada. *PLoS One*, 7(12), e48168. doi:10.1371/journal.pone.0048168
- Low, J., & Theriault, L. (2008). Health promotion policy in Canada: Lessons forgotten, lessons still to learn. *Health Promotion International*, 23(2), 200-206. doi:10.1093/heapro/dan002
- Mackett, R. L., & Thoreau, R. (2015). Transport, social exclusion and health. *Journal of Transport & Health*, 2(4), 610-617. doi:10.1016/j.jth.2015.07.006
- Mackey, S. (2005). Phenomenological nursing research: Methodological insights derived from Heidegger's interpretive phenomenology. *International Journal of Nursing Studies*, 42(2), 179-186. doi:10.1016/j.nurstu.2004.06.011
- Magnus, M., Herwehe, J., Murtaza-Rossini, M., Reine, P., Cuffie, D., Gruber, D., & Kaiser, M. (2013). Linking and retaining HIV patients in care: The importance of provider attitudes and behaviors. *AIDS Patient Care and STDs*, 27(5), 297-303. doi:10.1089/apc.2012.0423
- Mars, S. G., Bourgois, P., Karandinos, G., Montero, F., & Ciccarone, D. (2014). "Every 'never' I ever said came true": Transitions from opioid pills to heroin injecting. *International Journal on Drug Policy*, 25(2), 257-266. doi:10.1016/j.drugpo.2013.10.004

- Marshall, B. D. L., Milloy, M. J., Wood, E., Galea, S., & Kerr, T. (2012). Temporal and geographic shifts in urban and nonurban cocaine-related fatal overdoses in British Columbia, Canada. *Annals of Epidemiology*, 22(3), 198-206. doi:10.1016/j.annepidem.2011.12.004
- Mateu-Gelabert, P., Guarino, H., Jessell, L., & Teper, A. (2015). Injection and sexual HIV/HCV risk behaviors associated with nonmedical use of prescription opioids among young adults in New York City. *Journal of Substance Abuse Treatment*, 48(1), 13-20. doi:10.1016/j.jsat.2014.07.002
- McConnell-Henry, T., Chapman, Y., & Francis, K. (2009). Unpacking Heideggerian phenomenology. *Southern Online Journal of Nursing Research*, 9(1), 1-6.
- McWilliam, C. L. (2010). Phenomenology. In I. Bourgeault, R. Dingwall, & R. de Vries (Eds.), *The SAGE handbook of qualitative methods in health research* (pp. 229-248). Thousand Oaks, CA: SAGE Publications Inc.
- Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian facts*. Toronto, ON: York University School of Health Policy and Management. Retrieved from http://www.thecanadianfacts.org/The_Canadian_Facts.pdf
- Mill, J., Edwards, N., Jackson, R., Austin, W., MacLean, L., & Reintjes, F. (2009). Accessing health services while living with HIV: Intersections of stigma. *Canadian Journal of Nursing Research*, 41(3), 168-185.
- Montaner, J. S. G., Lima, V. D., Harrigan, P. R., Lourenço, L., Yip, B., Nosyk, B., . . . Kendall, P. (2014). Expansion of HAART coverage is associated with sustained decreases in HIV/AIDS morbidity, mortality and HIV transmission: The "HIV treatment as prevention" experience in a Canadian setting. *PLoS One*, 9(2), e87872. doi:10.1371/journal.pone.0087872
- Moore, H. N., Mao, L., & Oramasionwu, C. U. (2015). Factors associated with polypharmacy and the prescription of multiple medications among persons living with HIV (PLWH) compared to non-PLWH. *AIDS Care*, 27(12), 1443-1448. doi:10.1080/09540121.2015.1109583
- Moos, M., & Mendez, P. (2014). Suburban ways of living and the geography of income: How homeownership, single-family dwellings and automobile use define the metropolitan social space. *Urban Studies*, 52(10), 1864-1882. doi:10.1177/0042098014538679
- Mugavero, M. J., Norton, W. E., & Saag, M. S. (2011). Health care system and policy factors influencing engagement in HIV medical care: Piecing together the fragments of a fractured health care delivery system. *Clinical Infectious Diseases*, 52 Suppl 2, S238-S246. doi:10.1093/cid/ciq048

- Mukhi, S., Barnsley, J., & Deber, R. B. (2014). Accountability and primary healthcare. *Healthcare Policy*, 10(Spec issue), 90-98.
- Neutens, J. J., & Robinson, L. (2010). *Research techniques for the health sciences* (5th ed.). San Francisco, CA: Pearson Education, Inc.
- Ontario College of Pharmacists. (2012). *Understanding your pharmacist's expanded role*. Retrieved from <http://www.ocpinfo.com/library/brochures/download/Expanded%20Role%20Brochure%20Lette-size.pdf>
- Organisation for Economic Co-operation and Development [OECD] (2015). *DAC list of ODA recipients. Effective for reporting on 2014, 2015 and 2016 flows* [Internet]. Retrieved from <http://www.oecd.org/dac/stats/documentupload/DAC%20List%20of%20ODA%20Recipients%202014%20final.pdf>
- Paez, A., Mercado, R. G., Farber, S., Morency, C., & Roorda, M. (2010). Accessibility to health care facilities in Montreal Island: An application of relative accessibility indicators from the perspective of senior and non-senior residents. *International Journal of Health Geographics*, 9, 52. doi:10.1186/1476-072x-9-52
- Patton, M. Q. (2008). Evaluation criteria. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 302-304). doi:10.4135/9781412963909.n155
- Popay, J., & Mallinson, S. (2010). Qualitative research review and synthesis. In I. Bourgeault, R. Dingwall, & R. de Vries (Eds.), *The SAGE handbook of qualitative methods in health research* (pp. 289-306). Thousand Oaks, CA: SAGE Publications Inc.
- Pope, C., Mays, N., & Popay, J. (2007). *Synthesizing qualitative and quantitative health evidence: A guide to methods*. Berkshire, UK: Open University Press.
- Raphael, D. (2010). Social determinants of health: An overview of concepts and issues (pp. 145-179). In T. Bryant, D. Raphael, & M. Rioux (Eds). *Staying alive: Critical perspectives on health, illness and health care* (2nd ed.). Toronto, ON: Canadian Scholars' Press Inc.
- Reeves, S., Lewin, S., Espin, S., & Zwarenstein, M. (2010). *Interprofessional teamwork for health and social care*. Oxford, UK: Wiley-Blackwell Publishing Ltd.
- Region of Durham. (2016). *Overview report: Health neighbourhoods in Durham region*. Whitby, ON: Region of Durham. Retrieved from https://www.durham.ca/departments/health/health_statistics/health_neighbourhoods/overview_Report.pdf

- Reif, S., Whetten, K., Ostermann, J., & Raper, J. L. (2006). Characteristics of HIV-infected adults in the deep south and their utilization of mental health services: A rural vs. urban comparison. *AIDS Care*, 18(1), 10-S17. doi:10.1080/09540120600838738
- Reiners, G. M. (2012). Understanding the differences between Husserl's (descriptive) and Heidegger's (interpretive) phenomenological research. *Journal of Nursing & Care*, 1(5), 1000119. doi:10.4172/2167-1168.1000119
- Relf, M. V., & Rollins, K. V. (2015). HIV-related stigma among an urban sample of persons living with HIV at risk for dropping out of HIV-oriented primary medical care. *Journal of the Association of Nurses in AIDS Care*, 26(1), 36-45. doi:10.1016/j.jana.2014.03.003
- Reynolds, K. A., Mackenzie, C. S., Medved, M., & Roger, K. (2015). The experiences of older male adults throughout their involvement in a community programme for men. *Ageing & Society*, 35(3), 531-551. doi:10.1017/S0144686X13000858
- Rickles, N., Furtek, K. J., Malladi, R., Ng, E., & Zhou, M. (2016). Pharmacy student attitudes and willingness to engage in care with people living with HIV/AIDS. *American Journal of Pharmaceutical Education*, 80(3), Article 45.
- Rief, J. J., Hamm, M. E., Zickmund, S. L., Nikolajski, C., Lesky, D., Hess, R., . . . Roberts, M. S. (2017). Using health information technology to foster engagement: Patients' experiences with an active patient health record. *Health Communication*, 32(3), 310-10. doi:10.1080/10410236.2016.1138378
- Risher, K., Mayer, K. H., & Beyrer, C. (2015). HIV treatment cascade in MSM, people who inject drugs, and sex workers. *Current Opinion in HIV and AIDS*, 10(6), 420-429. doi:10.1097/coh.0000000000000200
- Ritsher, J. B., & Phelan, J. C. (2004). Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry Research*, 129(3), 257-265. doi:10.1016/j.psychres.2004.08.003
- Rodgers, B. L. (2008). Audit trail. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 44). doi:10.4135/9781412963909.n25
- Rothbauer, P. M. (2008). Triangulation. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 893-894). doi:10.4135/9781412963909.n468
- Sagrestano, L. M., Clay, J., Finerman, R., Gooch, J., & Rapino, M. (2014). Transportation vulnerability as a barrier to service utilization for HIV-positive individuals. *AIDS care*, 26(3), 314-319. doi:10.1080/09540121.2013.819403.

- Sarnquist, C. C., Soni, S., Hwang, H., Topol, B. B., Mutima, S., & Maldonado, Y. A. (2011). Rural HIV-infected women's access to medical care: Ongoing needs in California. *AIDS Care*, 23(7), 792-796. doi:10.1080/09540121.2010.516345
- Schnarrs, P. W., Rosenberger, J. G., Satinsky, S., Brinegar, E., Stowers, J., Dodge, B., & Reece, M. (2010). Sexual compulsivity, the internet, and sexual behaviors among men in a rural area of the United States. *AIDS Patient Care and STDs*, 24(9), 563-569. doi:10.1089/apc.2010.0117
- Shaw, S. N. (2008). More than one dollop of cortex: Patients' experiences of interprofessional care at an urban family health centre. *Journal of Interprofessional Care*, 22(3), 229-237. doi:10.1080/13561820802054721
- Silver, D., Blustein, J., & Weitzman, B. C. (2012). Transportation to clinic: Findings from a pilot clinic-based survey of low-income suburbanites. *Journal of Immigrant and Minority Health*, 14(2), 350-355. doi:10.1007/s10903-010-9410-0
- Smith, S. M., O'Kelly, S., & O'Dowd, T. (2010). GPs' and pharmacists' experiences of managing multimorbidity. *British Journal of General Practice*, 60(576), e285-e294. doi:10.3399/bjgp10X514756
- Statistics Canada. (2015). *Canada's population estimates: Age and sex, July 1, 2015*. Retrieved from <http://www.statcan.gc.ca/daily-quotidien/150929/dq150929b-eng.pdf>
- Syed, S. T., Gerber, B. S., & Sharp, L. K. (2013). Traveling towards disease: Transportation barriers to health care access. *Journal of Community Health*, 38(5), 976-993. doi:10.1007/s10900-013-9681-1
- Tan, E. C. K., Stewart, K., Elliott, R. A., & George, J. (2014). Pharmacist services provided in general practice clinics: A systematic review and meta-analysis. *Research in Social and Administrative Pharmacy*, 10, 608-622. doi:10.1016/j.sapharm.2013.08.006
- The Canadian Press. (2015, August 20). Fentanyl dangers: Toronto police warning of 'devastating impact'. *CBC News*. Retrieved from <http://www.cbc.ca/news/canada/toronto/fentanyl-dangers-toronto-police-warning-of-devastating-impact-1.3193395>
- Thorpe, L. E., Bailey, S. L., Huo, D., Monterroso, E. E., & Ouellet, L. J. (2001). Injection-related risk behaviors in young urban and suburban injection drug users in Chicago (1997-1999). *Journal of Acquired Immune Deficiency Syndromes*, 27(1), 71-78.

- Todres, L., & Wheeler, S. (2001). The complementarity of phenomenology, hermeneutics and existentialism as a philosophical perspective for nursing research. *International Journal of Nursing Studies*, 38(1), 1-8.
- Turcotte, M. (2008a). The city/suburb contrast: How we can measure it? Ottawa, ON: Statistics Canada. Retrieved from http://publications.gc.ca/collections/collection_2008/statcan/11-008-X/11-008-XIE2008001.pdf
- Turcotte, M. (2008b). Life in metropolitan areas: Dependence on cars in urban neighbourhoods. Ottawa, ON: Statistics Canada. Retrieved from http://publications.gc.ca/collections/collection_2008/statcan/11-008-X/11-008-XIE2008001.pdf
- van den Hoonaard, D. K. (2015). *Qualitative research in action: A Canadian primer* (2nd ed.). Don Mills, ON: Oxford University Press.
- Webel, A. R., Sattar, A., Schreiner, N., & Phillips, J. C. (2016). Social resources, health promotion behavior, and quality of life in adults living with HIV. *Applied Nursing Research*, 30, 204-209. doi:10.1016/j.apnr.2015.08.001
- Wilson, K., Elliott, S., Law, M., Eyles, J., Jerrett, M., & Keller-Olaman, S. (2004). Linking perceptions of neighbourhood to health in Hamilton, Canada. *Journal of Epidemiology and Community Health*, 58(3), 192-198. doi:10.1136/jech.2003.014308
- Wilson, M. G., Lavis, J. N., & Gauvin, F-P. (2016). Designing integrated approaches to support people with multimorbidity: Key messages from systematic reviews, health system leaders and citizens. *Healthcare Policy*, 12(2), 91-104.
- Yin, R. K. (2016). *Qualitative research from start to finish* (2nd ed). New York, NY: The Guilford Press.
- Zukoski, A. P., & Thorburn, S. (2009). Experiences of stigma and discrimination among adults living with HIV in a low HIV-prevalence context: A qualitative analysis. *AIDS Patient Care & STDS*, 23(4), 267-276. doi:10.1089/apc.2008.0168