

**ACCESS TO ORAL HEALTH CARE FOR PEOPLE LIVING WITH HUMAN  
IMMUNODEFICIENCY VIRUS ATTENDING A COMMUNITY-BASED PREVENTIVE  
PROGRAM IN BRITISH COLUMBIA**

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submitted by Iris Feng in partial fulfillment of the requirements for  
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## **Abstract**

**Objective:** It is important that people living with HIV/AIDS (PLWHA) receive routine oral health care due to their increased risk of oral complications. However, PLWHA have difficulty accessing oral health services for various reasons, including having to endure HIV-related stigma and discrimination. In 2011, the University of British Columbia (UBC) Dental Hygiene Degree Program (DHDP) implemented a preventive oral health program at the Positive Living Society of British Columbia (PSLBC), a non-profit organization supporting PLWHA. This study aims to assess the influence this type of service delivery has on access to oral health care for members of PSLBC.

**Methods:** A retrospective chart review of 170 PSLBC members who utilized the program services was conducted with descriptive analysis. Sixty-nine patient satisfaction surveys were also reviewed. Personal interviews with 10 members and one focus group comprised of 12 staff and administrative personnel were conducted. Audio-recordings were transcribed verbatim and coded thematically using N-Vivo® 11 software. Emerging themes were identified using the interpretative phenomenology approach following Penchansky and Thomas' theory of access.

**Results:** Of the 170 members who utilized the program, the majority (85.9%) were males and most (72.8%) lived where the program was easily accessible and convenient. Eighty-six members were routinely and currently using the services. The program helped members utilize their financial resources to receive other types of dental services. As members are influenced by their past traumatic experiences, they appreciated services were delivered in a safe manner and in a stigma-free setting. Members valued the opportunity to educate future dental professionals to

reduce HIV-related stigma. However, unmet dental needs could not be addressed in the program for some members and appear to be influenced by dimensions of access at referral clinics.

**Conclusion:** This community-based preventive dental program had multiple positive influences on access to oral health care for members of PLSBC; however, the referral pathway appeared to need improvement. Findings highlight that there is a need for dental professionals to address the interrelated dimensions of access in order to engage PLWHA in oral health care due to the influence of socioeconomic status, HIV-related stigma, and histories of trauma.

## **Lay Summary**

In 2011, the University of British Columbia (UBC) implemented a community-based dental preventive program at Positive Living Society of British Columbia (PLSBC), a non-profit organization supporting their members living with HIV/AIDS. This study aimed to determine the influence this program had on access to oral health care for the members. One-hundred seventy dental charts and 69 patient satisfaction surveys were compiled and summarized. Ten personal interviews with members and one focus group comprised of 12 PLSBC staff and administrative personnel were conducted. Findings highlight the need for dental professionals to address the different dimensions of access that influence oral health care for PLWHA due to their socioeconomic status, history of trauma, and HIV-related stigma.

## **Preface**

This thesis is an original intellectual work of the author Iris Feng. The author performed all components of the study including the research proposal, ethics approval, data collection, and data analysis. The University of British Columbia (UBC) Behavioral Research Ethics Board granted the ethics approval with certificate number BREB H17-02457. This research project was supported by the partnering organization, Positive Living Society of British Columbia (PLSBC). The author wrote, prepared, and submitted the manuscript.

## Table of Contents

<b>Abstract.....</b>	<b>iii</b>
<b>Lay Summary .....</b>	<b>v</b>
<b>Preface.....</b>	<b>vi</b>
<b>Table of Contents .....</b>	<b>vii</b>
<b>List of Tables .....</b>	<b>xii</b>
<b>List of Figures.....</b>	<b>xiii</b>
<b>List of Abbreviations .....</b>	<b>xiv</b>
<b>Acknowledgements .....</b>	<b>xv</b>
<b>Chapter 1: Introduction .....</b>	<b>1</b>
1.1      HIV and oral health.....	2
1.1.1      Global epidemiology.....	3
1.1.2      HIV surveillance in Canada .....	3
1.1.3      HIV surveillance in British Columbia .....	4
1.1.4      HIV treatment and care .....	5
1.1.5      90-90-90 target.....	6
1.2      HIV-related stigma.....	7
1.2.1      Beginnings of HIV-related stigma .....	8
1.2.2      Groups most influenced by HIV-related stigma .....	8
1.2.3      Impact of HIV-related stigma .....	9
1.2.4      Stigmatization by health care professionals.....	9
1.2.5      Stigmatization by dental professionals .....	10
1.3      HIV and oral health.....	12

1.3.1	Barriers to oral health care .....	13
1.3.2	Retention in oral health care .....	14
1.4	Positive Living Society of British Columbia .....	15
1.5	Community-based preventive dental program.....	15
1.6	Research question .....	16
<b>Chapter 2: Materials and methods.....</b>		<b>17</b>
2.1	Theoretical foundation and framework.....	17
2.1.1	Interpretative phenomenology .....	17
2.1.2	Conceptual framework.....	19
2.2	Data collection .....	20
2.2.1	Retrospective chart review.....	20
2.2.2	Patient satisfaction surveys .....	21
2.2.3	Personal interviews .....	21
2.2.4	Focus group.....	23
2.2.5	Field notes.....	24
2.3	Analyses.....	25
2.4	Rigour .....	26
2.4.1	Reflexivity.....	27
2.4.2	Member checking.....	29
2.4.3	Data saturation .....	30
2.4.4	Triangulation.....	31
<b>Chapter 3: Results.....</b>		<b>32</b>
3.1	Demographic characteristics .....	32

3.2	Patient satisfaction surveys .....	33
3.3	Oral health status.....	34
3.4	Attendance .....	35
3.5	Services delivered .....	35
3.6	Personal interviews and the focus group .....	36
3.6.1	Affordability .....	36
3.6.1.1	Under and unemployment.....	36
3.6.1.2	Limits of public benefits .....	38
3.6.2	Acceptability .....	39
3.6.2.1	Importance of trauma-informed care .....	39
3.6.2.2	HIV knowledge and sensitivity.....	43
3.6.2.3	Non-discriminatory attitude .....	45
3.6.2.4	Informative and attentive .....	46
3.6.2.5	Oversight of care.....	48
3.6.3	Accessibility.....	49
3.6.3.1	Location and service convenience .....	49
3.6.3.2	Socioeconomic context of the neighborhood.....	51
3.6.4	Accommodation.....	53
3.6.4.1	Self-disclosure of HIV status .....	53
3.6.4.2	Duration of appointment .....	55
3.6.4.3	Facility design.....	56
3.6.5	Availability .....	58
3.6.5.1	Addressing immediate dental needs.....	58

3.6.5.2	Referrals .....	60
3.6.5.3	Community dental clinic at PLSBC.....	61
3.6.6	Impact to members personally .....	62
<b>Chapter 4: Discussion .....</b>		<b>65</b>
4.1	Financial ability and resources.....	65
4.2	Influence of trauma .....	67
4.2.1	Provider characteristics .....	68
4.2.2	Clinic setting .....	69
4.2.3	Collaboration with PLSBC .....	70
4.3	Training future professionals .....	72
4.4	Self-perceived oral health .....	72
4.5	Dental treatment needs.....	73
<b>Chapter 5: Conclusion .....</b>		<b>75</b>
5.1	Implications and recommendations .....	75
5.2	Challenges and limitations.....	77
5.3	Conclusion .....	78
<b>Tables .....</b>		<b>80</b>
<b>Figures.....</b>		<b>92</b>
<b>Bibliography .....</b>		<b>93</b>
<b>Appendices.....</b>		<b>105</b>
Appendix A : Patient satisfaction survey .....	105	
Appendix B : Recruitment poster .....	106	
Appendix C : Member and staff participant consent .....	107	

Appendix D : Personal interview guide ..... 110

Appendix E : Focus group guide ..... 112

## **List of Tables**

Table 1 Demographic data .....	80
Table 2 Health conditions and status .....	81
Table 3 Dental history and concerns.....	83
Table 4 Patient satisfaction survey findings .....	84
Table 5 Examples of patient satisfaction survey written feedback .....	85
Table 6 Oral health conditions.....	86
Table 7 Attendance data.....	88
Table 8 Services delivered.....	89
Table 9 Demographic characteristics of members participating in personal interviews .....	90
Table 10 PLSBC staff and administration participating in the focus group .....	91

## **List of Figures**

Figure 1 Visual map of emerging themes .....	92
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## **List of Abbreviations**

- Acquired Immune Deficiency Syndrome (AIDS)
- Antiretroviral (ARV)
- Antiretroviral therapy (ART)
- Canadian Health Measures Survey (CHMS)
- Decayed, missing, or filled, teeth (DMFT)
- Dental Hygiene Degree Program (DHDP)
- Downtown Eastside (DTES)
- Heterosexual contact (HET)
- Human immunodeficiency virus (HIV)
- Human Papilloma Virus (HPV)
- Joint United Nations Programme on HIV/AIDS (UNAIDS)
- Men who have sex with men (MSM)
- Organization for Economic Co-operation and Development (OECD)
- People living with HIV/AIDS (PLWHA)
- People who inject drugs (PWID)
- Persons with disabilities (PWD)
- Persons with persistent multiple barriers (PPMB)
- Positive Living Society of British Columbia (PLSBC)
- Public Health Agency of Canada (PHAC)
- Trauma-informed care (TIC)
- University of British Columbia (UBC)
- World Health Organization (WHO)

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## **Chapter 1: Introduction**

According to the Canadian Academy of Health Sciences, Canada's existing model of predominate privately delivered dentistry may meet the needs of the general population, but it does not address the oral health inequities and the complex oral health needs of vulnerable and marginalized groups (CAHS, 2014). In this study, vulnerable groups are defined as those who have difficulty accessing Canada's oral health system, and include people with low income, those working without dental insurance, the elderly, Aboriginal peoples, refugees and immigrants, people living with disabilities, and people living in remote regions (CAHS, 2014). As people living with HIV/AIDS (PLWHA) are living with a chronic infection that can result in disability, they are often identified as vulnerable and are often marginalized. Marginalized groups are those who are excluded by the general society due to their differences such as in religion, politics, culture, gender, or financial status (Cook, 2008). Common marginalized groups within PLWHA include racial/ethnic minorities, substance users, the unstably housed, and the mentally ill (Brondani, et al., 2012; Cunningham et al., 2007). Most marginalized groups experience oral health inequities.

Oral health inequities are strongly linked with lower income and lack of dental insurance, yet groups with vulnerabilities and complex care needs are challenged with additional barriers to obtaining oral health care (Wallace et al., 2015). PLWHA experience far more complex issues related to stigma, fear of disclosure, discriminating acts, and social exclusion when accessing oral health care service (Chambers et al., 2015; Donnelly et al., 2016; Jesanni et al., 2019; Reuda et al., 2016). The lack of access to oral health care can have negative effects on the systemic health of PLWHA, thus affecting their overall quality of life (Benjamin, 2012).

Innovative strategies are needed to improve, expand, and sustain access to oral health care services for PLWHA (Cunningham et al., 2015). The Positive Living Society of British Columbia (PLSBC, 2018), located in Vancouver, is a non-profit organization advocating for the rights and issues of their members living with HIV/AIDS. To improve access to oral health care for PLWHA, the University of British Columbia (UBC) Dental Hygiene Degree Program (DHDP) in collaboration with the PLSBC developed a weekly, on-going preventive oral care program for members of the society. The program has been in place since September 2011 and has yet to be formally evaluated. This research sought to acquire information about the demographics of clinic attendees, their satisfaction with the clinic, and on how the program has influenced access to oral health care for the members.

## **1.1 HIV and oral health**

The Centres for Disease Control and Prevention (CDC, 2018) defines the Human Immunodeficiency Virus (HIV) as a retrovirus that attacks the body's immune system, specifically CD4 cells that defend the body against pathogens, infections, and illnesses. Over time without treatment, the amount of virus in the host may increase and the number of CD4 cells may decline. The immune system can no longer fight off diseases and the body becomes vulnerable to opportunistic infections. With multiple infections, a person can progress to have Acquired Immune Deficiency Syndrome (AIDS) (CDC, 2018; Sharp and Hahn, 2011). AIDS is recognized to be one of the most devastating diseases since the 1980's, infecting at least 60 million people and causing more than 25 million deaths worldwide (Sharp and Hahn, 2011). PLWHA are at increased risk for co-morbidities such as cardiovascular disease, diabetes, arthritis, and common co-infections such as tuberculosis, hepatitis B, hepatitis C, and syphilis

(CDC, 2018; Sharp and Hahn, 2011). HIV can be transmitted by sexual, percutaneous, and perinatal routes through bodily fluids such as blood, semen, rectal or vaginal fluids, and breast milk. Approximately 80% of adults acquire HIV through contact with mucosal membranes (CDC, 2018b; Sharp and Hahn, 2011).

### **1.1.1 Global epidemiology**

The latest Joint United Nations Program on HIV and AIDS (UNIAIDS, 2018) data covering 160 countries estimated that 36.9 million people were living with HIV by end of 2017. Of those, 2.1 million people live in western and central Europe and North America. These regions experienced the highest decrease of AIDS related death (32%) between 2010 and 2017. However, developing countries such as India, Kenya, Uganda, and certain countries in Sub-Saharan Africa, continued to have the greatest HIV/AIDS morbidity and mortality (UNIAIDS, 2018).

### **1.1.2 HIV surveillance in Canada**

The Public Health Agency of Canada (PHACb, 2018) estimated approximately 63,110 Canadians were living with HIV at the end of 2016. The HIV prevalence began to increase in the late 1990's due to new HIV infections and effective treatment options which increased the life expectancy of PLWHA (Bourgeois et al., 2017). The PHAC estimated 2,402 new infections occurring in Canada in 2017, slightly higher than the 2,344 cases reported in 2016. This is a 3% increase compared to 2016 and 17.1% since 2014 (Haddad et al., 2018). The national diagnosis rate increased slightly from 6.4 to 6.5 per 100,000 from 2016 to 2017. It was estimated that one in seven PLWHA is unaware or undiagnosed of their serostatus and remains infectious (PHACc, 2018).

In 2017, Ontario had the highest prevalence of HIV cases (38.9%), followed by Quebec (27.9%), and Alberta (11.7%). The largest age group diagnosed with HIV since 1985 in Canada had been among those of 30-39 years old, with 31.2% new HIV cases in 2017. The second proportion of new HIV cases continued to be the 50 years and older age group at 22.9%, followed by 40-49 year old age group at 22.4% in 2017 (Haddad et al., 2018).

Gay, bisexual, and men who have sex with men (MSM) continued to be the highest risk group to be diagnosed with HIV, and accounted for 46.4% of new HIV diagnoses in Canada in 2017 (Haddad et al., 2018). The second highest exposure group was reported to be 28.7% through heterosexual contact (HET) comprised of three groups: HIV infected individuals born in a country where HIV is endemic (11.5%), heterosexual contact with a person at risk (7.2%), and heterosexual contact with no identifiable risk (10.0%). People who inject drugs (PWID) was the third exposure category accounting for 16.3% of all reported HIV cases in adults (Haddad et al., 2018). Since 1998, Caucasians have accounted for the largest proportion of HIV cases with 34.5% in 2017, followed by 25.3% Black, and Indigenous people divided into 17.4% First Nations, 2.3% Métis, 0.2% Inuit, and 0.3% unspecified Indigenous in Canada (Haddad et al., 2018). The proportion of HIV cases in Indigenous people increased the most to 30% between 2015 and 2016 (PHAC, 2018a).

### **1.1.3 HIV surveillance in British Columbia**

The rate of HIV diagnoses in BC was 5.1 per 100,000 persons in 2016, similar with the rate in 2015, and a slight decrease compared to 5.6 in 2014 (BC Centre for Disease Control [BC CDC], 2017). In BC, the rate of AIDS cases was 1.4 per 100,000 persons and continues to decrease. Similar to Canada, BC has the same three highest exposure groups with new HIV

diagnoses, although there has been a decline of HIV exposure among PWID living with HIV due to increasing uptake of antiretroviral therapy (ART) and provincial harm reduction programs that have shifted drug using behaviour (PHAC, 2018b) thus decreasing significantly the new HIV diagnoses provincially (BC CDC, 2017). In regards to ethnicity, Caucasians have been gradually decreasing in the incidence of HIV, comprising of 46% of all cases in 2016 in BC, followed by 10% among Asians, and 9% among Indigenous people (BC CDC, 2017).

#### **1.1.4 HIV treatment and care**

Antiretroviral therapy (ART) is the standard treatment that combines antiretroviral (ARV) drugs to suppress the HIV virus (World Health Organization [WHO], 2017). It is recommended that a person diagnosed with HIV begin ART as soon as possible to prevent disease progression, to limit its transmission, and to improve individual and public health outcomes (Grinsztejn et al., 2014; Günthard et al., 2016). With greater potency and convenience, ART is considered both safe and tolerable, with the potential to achieve lifelong viral suppression while reducing the risk of viral resistance (Grinsztejn et al., 2014).

The perceived lack of need for ART and HIV care are commonly cited reasons for not initiating or discontinuing ART (Dombrowski et al., 2015). However, if ART is initiated at a CD4 count of 350-550 cells/mm<sup>3</sup>, the risk of progression to AIDS is reduced. Likewise, if a CD4 count of more than 250 cells/mm<sup>3</sup> and an undetectable viral load of less than 50 copies/mL of the virus are achieved, the likelihood of restoring the immune system is increased. Furthermore, immune recovery can be achieved if new CD4 cells are produced to replace those that are lost during HIV infection (CDC, 2018c; Günthard et al., 2016).

ART has been effective when there is early HIV diagnosis, rapid linkage to health care, continuous retention in care, and uninterrupted access and adherence to ART (Grinsztejn et al., 2014). As a result, HIV mortality and transmission rates were substantially reduced with the uptake of ART and PLWHA can expect to have a longer lifespan (Ford et al, 2017; Günthard et al., 2016; Nakagawa et al., 2013).

### **1.1.5 90-90-90 target**

In 2014, as a global commitment to address the HIV epidemic and to eliminate AIDS as a public health threat by 2030, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the WHO aimed to reach the “90-90-90 target” (that is, to diagnose 90% of people living with HIV, to provide treatment for 90% of those diagnosed with HIV, and to achieve viral suppression for 90% of those treated) by 2020 and the “95-95-95” target was set for 2030 (Ford et al., 2017; Lima et al., 2017; PHAC, 2018a). The PHAC produces reports as a national response to HIV and AIDS, providing a direction towards future HIV prevention, efforts, and interventions. The PHAC statistics have reported approximately 86% of PLWHA in Canada were diagnosed, 81% of those diagnosed were on treatment, and 91% of those on treatment achieved a suppressed viral load by 2016.

The UNAIDS estimates that in BC by the year 2020, 90% of PLWHA will be diagnosed, 91% will be on ART, and 90% will be suppressed, thus reaching the 90-90-90 target. Current models also show that BC will be able to reach the 95-95-95 target by 2030 with estimates of 97%, 99%, and 97% respectively. BC’s current and projected achievements could be due to the fact that it is the only jurisdiction in Canada that provides universal coverage and fully subsidized ART, with continued laboratory and medical monitoring. Furthermore, since 2003,

BC has normalized HIV testing in the general population, facilitated access to free ART, and provided extensive harm reduction strategies. As a result from improved HIV care compliance and response to ART, there has been greater engagement in HIV care and reduced HIV transmission (Lima et al., 2017).

## **1.2 HIV-related stigma**

Despite advancements in HIV treatment, stigma remains one of the biggest challenges PLWHA face due to perceptions and judgements linked with HIV (Chambers et al., 2015; Gagnon, 2015; Rueda et al., 2016). Stigma is defined as a common attribute enforced on any group of people, therefore reducing the status of that particular group (Chambers et al., 2015). HIV-related stigma can develop through identified characteristics including socially devalued attributes of HIV, modes of transmission, and the judgemental attitudes towards groups impacted by HIV (Chambers et al., 2015; Rueda et al., 2016). HIV-related stigma is strongly associated with depression, risky sexual behaviours, lower social support, lower levels of adherence to ART, and lower usage of health and social services (Rueda et al., 2016).

Stigma further impacts the mental, emotional, physical and psychological well-being, life satisfaction, and quality of life of PLWHA (Chambers et al., 2015; Rueda et al., 2016). There are three forms of stigma that are directly associated with HIV. Enacted stigma is when an individual receives negative reaction from others, while vicarious stigma refers to hearing of others stigmatized. Finally, internalized stigma is developed when there is internalization of negative self-worth or value (Donnelly et al., 2016; Loutfy et al., 2016; Rueda et al., 2016). All three forms have major contributions in the perceptions and actions of PLWHA when seeking health services and resources (Donnelly et al., 2016).

### **1.2.1 Beginnings of HIV-related stigma**

Donnelly et al. (2016) found that the reasons for HIV-stigma are multifaceted and are often experienced internally, in social circles, romantic relationships, and the workplace. Stigma begins from HIV diagnosis with internal stigma initially driven by what was seen and heard prior to their own HIV diagnoses, while feelings of blame and guilt surge in oneself for becoming infected with HIV. Death and dying are often immediate and central thoughts after the HIV diagnoses. Stigma is further influenced by societal views and personal experiences from reactions told by others beforehand, and self-perceptions of having HIV (Donnelly et al., 2016).

Stigma plays an important role in disclosure of one's HIV positive serostatus to loved ones, social support networks, and health care providers. In many instances, PLWHA have a fear of disclosing their HIV status due to the risk of marginalization, isolation, and social exclusion (Wagener, 2017). Based on individual experiences of HIV and preconceived thoughts of HIV, internalized stigma is then positively or negatively influenced by interaction with social networks, health care system, and HIV-specific community organizations (Chambers et al., 2015; Donnelly et al., 2016).

### **1.2.2 Groups most influenced by HIV-related stigma**

Understanding HIV-related stigma is complex as it can involve intersecting cross-cultural differences, social identities and inequities, structural inequities, socioeconomic status, gender, sexual orientation, and social processes (Chambers et al., 2015). The female gender and non-white ethnic minorities experience greater HIV-related stigma. In particular, high levels of HIV-related stigma among Black women indicate sexist and racist stereotypes in the HIV construct (Gagnon, 2015). In BC, marginalized groups, including Indigenous people, refugees and

immigrants appear to be the most impacted by HIV-related stigma (Brondani et al., 2016; Donnelly et al., 2016). Indigenous people tend to experience great HIV-related stigmatization and stereotyping towards their ethnicity, which might constitute double or even triple stigma (Donnelly et al., 2016).

### **1.2.3 Impact of HIV-related stigma**

HIV-related stigma is a broad and global phenomenon existing within multiple social domains, including health care settings (Gagnon, 2015). Acts of discrimination in healthcare environments is commonly experienced by PLWHA including denial of care, confidentiality breaches, negative attitudes, and humiliating practices by health care providers (Chambers et al., 2015; Gagnon 2015). These acts may be due to stereotypes unconsciously held towards PLWHA due to assumed undesirable characteristics and behaviours linked to this group such as drug seeking, intravenous drug use, or unprotected sex (Brondani et al., 2016; Gagnon, 2016). Furthermore, HIV and AIDS have been viewed as a concept of “deviant sexuality” that involve lesbian, gay, bisexual, and queer persons, suggesting HIV/AIDS disease as a punishment (Loutfy et al., 2012). Consequently, HIV-related stigma deters PLWHA to seek health services and resources in order to prevent potential consequences from disclosing their serostatus to others and experiencing internalized shame (Rueda et al., 2016), thus preventing engagement in life-saving care (Donnelly et al., 2016).

### **1.2.4 Stigmatization by health care professionals**

The fear of stigma can deter individuals from HIV testing and prevent disclosure of their HIV seropositive status in numerous health care settings (Donnelly et al., 2016; Kinsler et al.,

2007). Hennen and Brucket (2012) described that the health care environment can operate as an institutional system of societal perceptions of HIV and systems of power, known as structural stigma. Structural stigma is assumptions manifested in policies, practices, and discourses as a response from institutions, agencies, and individuals to a stigmatized group. Such instance of structural stigma would be that PLWHA are expected to self-disclose their HIV status in health care systems. They might be managed as risky cases, potentially leading to unethical, arbitrary, and discriminatory practices such as altering the routine practice of universal precautions (Hannem and Bruckert, 2012). Additionally, if there is a perceived sense that the health care provider is uncomfortable treating PLWHA, they become reluctant to proceed with HIV treatment or utilize medical services. With delay in treatment and loss of follow-up appointments, PLWHA may require more medical interventions due to late clinical presentations at more advanced stages of HIV infection (Kinsler et al., 2007). Health care venues such as emergency rooms, walk-in medical clinics, and dental clinics are often perceived as environments with increased levels of stigma and discrimination (Donnelly et al., 2016).

### **1.2.5 Stigmatization by dental professionals**

Similar to health care settings, PLWHA may have to contain their fear and disclose their HIV status when accessing dental care (Brondani et al., 2016). HIV status disclosure poses a risk of changing the patient-dental provider relationship (Brondani et al., 2012), and PLWHA have reported being denied care, receiving sub-standard care, or being inappropriately charged for dental services (Brondani et al., 2016). Dental providers who deny access to PLWHA do not follow the ethical standards to treat individual dental needs (Brondani et al., 2012; Canadian Dental Association [CDA], 2017). According to the CDA (2017), current guidelines state that

dentists cannot refuse to treat patients based on the HIV positive status. Nevertheless, PLWHA have described experiences of being directly or indirectly labelled, stereotyped, excluded, isolated, and discriminated against by dental providers. To avoid this stigmatization and discrimination, PLWHA tend to seek dental providers who have specific attributes such as knowledge, experience working with PLWHA, and those who are caring and non-judgemental (Brondani et al., 2012; Chambers et al., 2015).

Dental providers who refuse to treat PLWHA rationalize their decision as fear from staff and other patients, fear of increased personal risk, fears related to cross-infection, and financial burden (McCarthy et al., 1999). Additionally, dental providers may engage in stigmatizing behaviours due to lack of HIV knowledge, limited professional experience with PLWHA, negative attitudes, beliefs, and emotional responses towards PLWHA, which may result in the lack of providing quality care to these individuals (Brondani et al., 2016; Donnelly et al., 2016; Oboro et al., 2010). Dental providers may have also not updated their HIV education or did not have the opportunity to care for PLWHA throughout their careers (Donnelly et al., 2016). The lack of HIV knowledge, awareness, education, and exposure emphasizes the need for appropriate training and HIV education at undergraduate, postgraduate, and continuing education programs (Oboro et al., 2010). In order to better serve this population, HIV education should emphasize sensitivity training on how the display of attitudes, actions, and communications can be perceived as discriminatory and stigmatizing (Donnelly et al., 2016). This appears to be having some impact as younger dentists have been found to be less likely to refuse treatment to PLWHA, possibly due to more formal training and a stronger sense of ethical responsibility (McCarthy et al., 1999).

### **1.3 HIV and oral health**

Historically, dental providers have been an important ally in HIV primary care as they are often the first to recognize oral manifestations or symptoms of patients who are unaware of their HIV positive status (Brondani et al., 2016; Oboro et al., 2010). Timely diagnosis and access to HIV care and treatment is critical in reducing transmission (Brondani et al., 2016; Hutchinson et al., 2012, PHAC, 2018a). Before the introduction of ART in HIV treatment, oral lesions were commonly observed among PLWHA such as oral candidiasis, herpes simplex lesions, linear gingival erythema, and oral hairy leukoplakia (de Almeida et al. 2017; Dios et al., 2000; Nittayananta et al., 2010).

The initiation of ART has caused a dramatic decline in the prevalence of HIV-associated oral lesions, particular oral candidiasis due to suppressed viral replication and restoration of the immune system (Ceballos-Salobrena et al., 2000; Dios et al., 2000; Nittayananta et al., 2010). Other explanations involve a decline in toxic habits such as intravenous drug use, and improved oral hygiene and oral health care, typically seen in PLWHA engaged in long-term HIV care (Dios et al., 2000). The use of ART has also reduced clinical manifestations of oral hairy leukoplakia, necrotizing ulcerative gingivitis, necrotizing ulcerative periodontitis, necrotizing ulcerative stomatitis, and Kaposi sarcoma (de Almeida et al., 2017). However, PLWHA may still show an increased risk of oral lesions as well as orofacial pain, and cervical caries compared to their counterparts on long-term ART (Nittayananta et al., 2010).

On the other hand, the prolonged use of ART and a recovered immune system puts PLWHA at risk of developing oral mucosal hyperpigmentation as a result of increased melanin production (de Almeida et al. 2017; Nittayananta et al., 2010), as well as an increased incidence of HIV-associated salivary gland disease, parotid gland enlargement, and Human Papilloma Virus (HPV)

associated oral warts (Burger-Calderon et al., 2016; King et al., 2002). Xerostomia is a common side effect with ART medications, yet inconsistent findings cannot confirm whether a change in salivary gland function increases oral dryness in association with ART (King et al., 2002; Nittayananta et al., 2010).

Given the increased risk of oral complications and the potential for compromised oral health, it is important that PLWHA receive routine oral assessment and care (Rajabiun et al., 2012). Poor oral hygiene habits and lack of preventive dental care increase the risk of periodontal disease, the need for restorative procedures and treatment from increased caries activity (Burger-Calderon et al., 2016; Tobias et al., 2012), and may result in poorer physical and mental health (Rajabiun et al., 2012). Poor oral health can also interfere with chewing ability and dental function, affecting the individual's quality of life (Giuliani et al., 2005; Tobias et al., 2012).

### **1.3.1 Barriers to oral health care**

In addition to stigmatization and discrimination, PLWHA face other barriers to accessing oral care. Lack of dental insurance or financial challenges is a significant barrier due to Canada's predominantly private administered and delivered oral health care system (Jeanty et al., 2012; Tobias et al., 2012). People with no dental insurance were six times more likely to avoid dental visits and treatment compared to their insured counterparts (Thompson et al., 2014). Results from the 2007-2009 Canadian Health Measures Survey (CHMS) report 32% of Canadians without dental insurance, and of those, 53% of adults between ages 60 to 79 and 50% of those with lower income without dental insurance (Health Canada, 2010).

The lack of public dental services, inflexible dental workforce, and lack of national oral health care standards also does not facilitate equitable access for all people living in Canada. The

position from the CDA (2017) and the vision of the CAHS (2014) state that the provision of equitable access to oral care for all Canadians has not been achieved. Canada ranks lower among the Organization for Economic Co-operation and Development (OECD) countries in public financing of oral health care.

PLWHA may face additional barriers based on geographic, social, cultural, and community factors (Pellowski, 2013). Social determinants and conditions such as disability, chronic illness, addiction, poverty, confidentiality-related issues, lack of access to support services, and limited oral health literacy may also affect engagement with oral health care (Barnes et al., 1996; Benjamin, 2012; Pellowski, 2013).

### **1.3.2 Retention in oral health care**

Positive patient-provider interaction plays an important role in retention in oral health care as patients are more likely to disclose their HIV status and return for oral care (Barnes et al., 1996; Tobias et al., 2012). Patient education about oral hygiene, tobacco cessation, and nutritional counselling are strongly associated with care retention (Tobias et al., 2012). Due to the increased anxiety and vulnerability PLWHA experience, they seek dental providers who are reliable, non-judgemental, and reassuring. Facilitation of open communication and encouraging active engagement with patients positively influences dental care seeking behaviour (Dang et al., 2017; Rajabiun et al., 2012). Moreover, contextual factors such as treatment by staff, waiting times, and oral health messages are influential (Lemay et al., 2012; Rajabiun et al., 2012). PLWHA who have a good patient-provider relationship tend to understand the link between oral health and its impact on their HIV status which motivates them to maintain their oral care (Lemay et al., 2012). PLWHA are also more likely to access routine oral health care when they

are driven to improve their personal appearance, which reduces their social isolation and improves their self-esteem (Rajabiun et al., 2012).

#### **1.4 Positive Living Society of British Columbia**

The Positive Living Society of British Columbia (PLSBC, 2018) is a non-profit organization founded in 1986 to create a community for PLWHA to advocate for their rights. Their vision statement is that PLWHA in BC are “*healthy and free to lead purposeful and actively engaged lives in an accepting, inclusive community*”, hence representing the voices and experiences of PLWHA. Only PLWHA members registered with PLSBC can utilize services offered by the organization, with nearly all their staff members also being HIV positive as a requirement. There are currently about 5,900 registered members at PLSBC. PLSBC offers different programs and resources to meet the needs of their diverse members including health and wellness programs, peer navigation services, healing retreats, prison outreach services, spiritual workshops, and treatment outreach services (PLSBC, 2018).

#### **1.5 Community-based preventive dental program**

Community-based programs that incorporate multidisciplinary care and collaboration among health and social care providers can engage and help to retain PLWHA in oral health care, with emphasis on the influence of oral health on overall health (Bachman et al., 2012). With multiple considerations and barriers, PLWHA tend to reach out to HIV-specialized resources and networks that support their general well-being (Donnelly et al., 2016). A partnership was formed between PLSBC and the University of British Columbia (UBC) Faculty of Dentistry in 2009 to address the dental needs of members. In September 2011, the implementation of a preventive

dental clinic in collaboration with the UBC Dental Hygiene Degree Program (DHDP) at PLSBC was launched. This program was undertaken to train and increase HIV awareness to undergraduate dental hygiene students, as well as increase access to preventive oral health care for PLWHA. To date however, the delivery of this preventive dental program has not been evaluated. It is therefore unclear if and how the program is having an influence on access to oral health care for PLWHA.

## **1.6 Research question**

This study was undertaken to answer the following research question: *how does the implementation of preventive dental services at PLSBC influence access to oral health care for the members?*

Information gained from this study will aid in a better understanding of aspects of this program that influenced oral health care for PLWHA that can inform future modifications and potentially the development and delivery of other dental services in similar organizations.

## **Chapter 2: Materials and methods**

For my study, I compiled responses from 69 patient satisfaction surveys for overall member feedback of the program. I then conducted a retrospective chart review totalling 170 members to gain a general understanding of the population's characteristics including their oral health status, dental treatment needs, attendance, and services provided. I then used a qualitative research approach to explore the experiences of navigating and accessing dental care of members attending the program at PLSBC. This was completed through conducting 10 personal interviews with members and a focus group comprised of 12 staff and administrative personnel. I used an interpretative phenomenology approach using a conceptual framework of access to explain my qualitative findings in relation to my research question.

### **2.1 Theoretical foundation and framework**

#### **2.1.1 Interpretative phenomenology**

The philosophical approach of phenomenology was first introduced by philosopher Edmund Husserl and sociologist Alfred Schutz in the 1960's, proposing that the "essence" of objects can only be understood through the consciousness and studying the subjective perceptions and experiences of these objects (Green and Thorogood, 2014). Phenomenological approaches focus on subjectivity and the attempt to identify the meaning of the lived experiences of study participants (Green and Thorogood, 2014; Lopez and Willis, 2004). According to Lopez and Willis (2004), the first main phenomenological approach proposed by Husserl was eidetic, or also known as descriptive phenomenology, which requires the researcher to set aside all prior personal and expert knowledge and biases to grasp the essential lived experiences of participants in order to gain narratives and core concepts. Descriptive phenomenology uses bracketing where

the researcher sets aside his/her preconceptions, ideas, and personal knowledge to listen and reflect on lived experiences of participants (Lopez and Willis, 2004).

However, Martin Heidegger challenged the work of Husserl and argued that participants' narrative should be interpreted in various contexts and meanings (Cohen and Omery, 1994; Leonard, 1999). Heidegger proposed hermeneutic, or interpretative phenomenology, in which researchers strive to go beyond the human experience in order to unfold hidden meanings that may not be apparent to participants (Lopez and Willis, 2004). Interpretative phenomenologists analyze historical, social, cultural, and political forces or specific conditions that influence the choices participants make, defined as situated freedom (Leonard, 1999; Tuohy et al., 2013). The interpretative approach argues that it cannot be possible to set aside all conscious and unconscious assumptions, preconceptions, and influences, but instead these can be acknowledged to reflect and understand other people's meanings, thus integrated into research findings (Tuohy et al., 2013).

Rather than bracketing, interpretative phenomenology uses "hermeneutic circle", a process of continuous questioning and re-examination, achieved through dialogue and openness between the researcher and participant to unfold the true meaning of the experience (Tuohy et al., 2013). With the interpretative approach, researchers may utilize a pre-existing theoretical orientation to focus on the research inquiry and make decisions regarding sample, subjects, and research questions, or a conceptual framework to interpret data, generate findings, and help reflect the realities of study participants (Lopez and Willis, 2004). Both the theoretical orientation and conceptual framework are expert knowledge that guide inquiries and make the inquiries meaningful (Lopez and Willis, 2004).

## **2.1.2 Conceptual framework**

Access is fundamental in measuring the utilization, performance, and satisfaction in health care systems (Levesque et al., 2013; Saurman, 2016). However, Penchansky and Thomas (1981) proposed that access is an ambiguous concept with multiple meanings interpreted across various authors and is difficult to measure. The term access has been defined commonly as the entry to use, the assumed availability of supply and resources, or factors that influence the level of use. Amongst many conceptions, authors described access to health care as a supply and demand type of system (Feldstein, 1966), dimensions of equity in access (Guildford et al., 2002), and characterized access to be influenced by predisposing, enabling, and health system factors (Andersen and Newman, 1973). The framework by Penchansky and Thomas (1981) defined access as five interlocking dimensions describing the relationship between the patient and health care system on individual terms: availability, accessibility, accommodation, affordability, and acceptability. Availability refers to the type of existing services that meet the patient's needs. Accessibility is the relationship between the location of supply and the patient, including transportation, travel time, distance, and cost. Accommodation is how supply resources are organized to tailor the patient's needs, such as the appointment system or opening hours. The set of prices and services the patient is required to pay is affordability. Lastly, acceptability is the patient's attitudes and preference in regards to the personal and practice characteristics of the provider, also referring to the patient's social and cultural beliefs to accept aspects of the service delivered (Penchansky and Thomas, 1981).

According to this framework, access is conceptualized between the characteristics of health care providers and services, and the characteristics and expectations of the patient. Consequently, the outcomes of patient satisfaction are not linear but interrelated between the five dimensions,

affecting service utilization and provider practice patterns (Levesque et al., 2013; Penchansky and Thomas, 1981). This framework was appropriate to use as the conceptual framework in my qualitative research as I was exploring access to oral health services, and needed to determine specifically which relationships or aspects of access influenced members to utilize the program. With this framework, it was anticipated that program utilization, satisfaction, and provider practice could be assessed and identified specifically in relation to oral health care.

## **2.2 Data collection**

### **2.2.1 Retrospective chart review**

Upon the ethics approval granted from the UBC Behavioural Research Ethics Board (BREB H17-02457), UBC patient dental charts of PLSBC members were accessed to extract data for anonymous analysis. From September 2011 to December 2017, 170 members had utilized the services delivered by fourth year dental hygiene students. Information from patient dental charts was retrieved and compiled into four main categories: demographics, oral health status, attendance pattern, and services delivered.

Demographics revealed characteristics of members, their health conditions, status of their dental insurance, and reasons why they were utilizing the program. Oral health status described the oral health condition of members such as the presence of existing dentition, suspected caries lesions, decayed, missing, or filled, teeth (DMFT), periodontal diseases, oral lesions, and restorative treatment needs. The type and amount of services delivered was summarized to describe the overall pattern of service utilization including assessments, clinical care, education and referrals. Finally, attendance data was retrieved to document how the program has been utilized from number and reasons of new, returning, and discontinued members.

## **2.2.2 Patient satisfaction surveys**

Members were requested to complete patient satisfaction forms after their appointments to provide feedback anonymously. Members who utilized the clinic more than once may have filled out more than one form. A total of 69 satisfaction forms were completed from 2016 to 2017, with responses based on a five-point Likert scale from strongly agree to strongly disagree (Appendix A). Members were asked to rank their degree of satisfaction such as with undergraduate dental hygiene students, the instructor, program design including equipment, time, and referrals, and the overall care. Members were also able to comment regarding their oral health education and suggested improvements for the program. Responses were compiled, summarized, and used to develop my interview guide to conduct the qualitative aspect of my study.

## **2.2.3 Personal interviews**

Personal interviews provide a perspective from the participants' world to understand the significance of participants' experiences (Kvale, 1996). To evaluate the program, it was important I obtained feedback from members who had experience with the program. Interviews would explore the members' perspective, whether the program had influenced access to oral health care for them. Therefore, members of PLSBC who have utilized the program were recruited to participate in personal interviews to illicit their past and current experience accessing the oral health care system and this program (Appendix B). As my questions may potentially probe into sensitive topics such as HIV stigma and discrimination, HIV serostatus disclosure, and past negative dental experiences, I chose to conduct personal interviews to explore the detailed insights into participant's inner thoughts, feelings, experiences, beliefs, and knowledge

instead of group discussions (Lambert and Loiselle, 2008). Members were more likely to feel more comfortable and reveal personal beliefs when assured confidentiality of the information they provided (Gill et al., 2008).

Inclusion criteria required participants to be a past or current patient of the program, ability to communicate in English, and commitment to a one-hour, face-to-face interview. Recruitment posters outlining details of the study and interview were placed on bulletin boards and visible areas at PLSBC. Members known to the collaborators who may have substantial insight into the research questions were approached and offered to participate in the interview as well. Students and the instructor also informed current patients utilizing the program when this project was in progress of recruiting participants. Members interested in the interview were instructed to contact me for further information about the study, and to arrange a time for the interview. Therefore, a convenience sample was obtained as the members volunteered to participate in the interview.

With consent obtained (Appendix C), I conducted 10 individual interviews to capture responses related to the core objectives of my study (Jamshed, 2014) following a semi-structured interview guide (Appendix D) consisting of questions based on my literature review, overall feedback from patient satisfaction forms, collaborator input, and pertinent to the research question. The questions were arranged under three themes: members' past dental experiences, members' experience using the program (questions here were focused on the Penchansky and Thomas' framework), and members' satisfaction and suggested improvements for the program. A new topic arose during my fifth interview that related to members' perception that the program is an opportunity to educate students in HIV sensitivity and awareness. This was incorporated into the next interviews in order to gain further insight into the importance of HIV education by

members during interactions with the students in the program. Each interview was conducted in a private space at PLSBC where participants could easily access the familiar and comfortable setting. Each interview lasted from 35 minutes to one hour and was audio-recorded. Participants' general demographic information was also obtained throughout the interview.

#### **2.2.4 Focus group**

Unlike personal interviews, focus groups allow participants to engage in a discussion to generate a range of rich data, increasing the depth of the phenomenon. A focus group is a group of individuals with certain common characteristics who discuss a given topic or issue, characterized by a prompt or stimulus often introduced by a moderator, and the collective interaction and view of the group (Guest et al., 2017). However, there must be attention towards the interaction and individual insights to identify the group dynamics and context (Lambert and Loiselle, 2008). A participant may or may not choose to share a certain perspective depending on the context and interaction created in the discussion. If a discussion evolves into deeper interaction and understanding among the participants, additional data may be produced (Lambert and Loiselle, 2008).

The focus group comprised of PLSBC staff and administrative personnel with some insight about the program was recruited by two collaborators (Director of Programs and Services, Coordinator of Treatment and Wellness program). The coordinator of treatment and wellness program was involved with the program for several years and served as a collaborator between the society and the UBC. Staff and administrative personnel consisted of peer navigators, program coordinators, and directors from different departments at PLSBC. Through purposive sampling, a total of 12 individuals were recruited to participate in the focus group. Qualitative

researchers suggest focus groups should range from six to 12 participants. A number less than six participants may be ineffective to keep the synergy of the group and to produce rich information, while a number greater than 12 may be cumbersome to manage and hinder opportunities to full participation (Guest et al., 2017). In my focus group, there were two participants in particular who did not engage as actively as other staff, and were approached after the focus group to offer them the opportunity to provide further feedback about the program. Neither participant had opposing views of what was discussed and had no comments regarding new information.

Participants in the focus group were asked to describe the perceived influence of the program on their members with regard to the concept of access, and were also given the opportunity to provide suggestions how to improve the current program (Appendix E). During the focus group, I observed no disputations among the staff but instead agreements and additional comments regarding the previous speaker and topic. Directors often had perspectives regarding the program's influence on the organization, academia, community, and research while coordinators and peer navigators offered their views about members mostly. The focus group was also audio-recorded, with memos identifying each staff participant's comments.

## **2.2.5 Field notes**

Qualitative field notes are recorded by researchers prior to, during, or after an observation or interaction in order to aid in the analysis of the phenomena (Maharaj, 2016). Field notes primarily aid to construct description of the study's context, to prompt the researcher to observe the physical environment, to encourage the researcher in reflexivity and bias identification, and to increase trustworthiness of the data (Phillipi and Lauderdale, 2018). My field notes included details of the initial encounter, description and mood of the participant, general observations of

the participant's reactions and non-verbal language towards the questions, recurrent themes, difficulties encountered, and other post-interview comments. Field notes were written immediately after each interview which enabled me to gradually become a more attentive observer. As it was difficult to moderate the focus group and take field notes at the same time, my colleague recorded field notes and identified staff participants' responses and those who were less engaged in the discussion. My documentation of field notes was helpful to assess the context and meaning for each transcript and for me to proceed in critical reflection and self-awareness.

### **2.3 Analyses**

The patient satisfaction surveys and retrospective chart review was analyzed with excel using univariate descriptive statistics to represent the findings and identify the recurring patterns and characteristics of the members who attended the program. Further statistical analysis was not undertaken. The quantitative chart data was reported as frequency distribution, central tendency, or dispersion. The data findings were complimentary to the core of my study and increased understanding of the target population and their dental needs.

Following each interview and the focus group, the audio-recording was transcribed verbatim either by me or through an automated software transcription service, which were later checked and edited by me for accuracy. The identity of the participants was removed and replaced with a numerical or alphabetical pseudonym. Each transcript was read multiple times and coded thematically using N-Vivo® 11 software. Coding and emerging thematic analysis was completed accordingly using the interpretative phenomenology approach with Penchanskys and Thomas' concept of access as the framework. Constant comparative coding and analysis were completed after each interview to identify and interpret emerging and recurrent codes and themes.

My committee members and supervisor also compared their coding of one interview to provide directions and ensure the validity of my coding.

An iterative and systematic approach was used to analyze the interview and focus group transcripts and to construct codes, categories, and themes, which were then arranged under domains of access that they pertained most prominently in. I assigned a code to statements made by participants that seemed relevant and meaningful to the research question. As my list of codes grew as I analyzed the transcripts, a total of 99 codes were then sorted into 20 categories that described an aspect of the phenomenon. Similar categories were grouped into 16 themes structured into the five domains of access. One additional theme did not seem to fit under any aspects of access yet influenced the continued utilization of the program was represented as a sixth domain. A thematic map was created to help examine the relationship as some of my themes overlapped and was interrelated with and also applicable to more than one domain (Figure 1). Themes were organized under the domain that was most prominent and influenced that particular aspect of access.

## **2.4 Rigour**

Rigour refers to the state of being exact, careful, and with strict precision integrated to the qualitative research process to reduce the potential of subjectivity (Cypress, 2017; Stewart et al., 2008). Without rigour, qualitative research is subject to being considered fictional and worthless in explaining the phenomenon (Tobin and Begley, 2004; Rettke et al., 2018).

David and Dodd (2002) argued rigour to be a generalized concept of quantitative bias, often understood in concepts of objectivity, reliability, replication, validity, and structure in a neutral approach. They proposed another meaning of rigour, in terms of carefulness, sensitivity, respect,

reflection, conscientiousness, awareness, and openness in order to capture the attentiveness in qualitative research. However, Lincoln and Guba (1985) proposed that trustworthiness is the central concept in rigour, referring to the quality, authenticity, and truthfulness, ensuring the research process has been carried out correctly. Since then, many authors have debated the issues of rigour, from reliability, validity, credibility, dependability, and trustworthiness, developing standards, checklists, and guidelines to evaluate the quality of qualitative inquiry (Cypress, 2017; Golafshani, 2013; Morse et al., 2012; Seale, 1999). Some checklists of rigour include purposive sampling, multiple coding, triangulation, member checking, or respondent validation (Stewart et al., 2008).

Regardless of the various approaches and criteria, rigour is about integrity and competence that demonstrate the standards for ethics and quality in qualitative research (Lincoln, 1995). To that end, qualitative researchers should provide a detailed and transparent description of the study method and data to demonstrate a logical approach and for other researchers to understand the explanation of the phenomenon (Stewart et al., 2008; Tobin and Begley, 2004). Below I outline several strategies I built throughout my research process to attend to the rigour for my study.

#### **2.4.1 Reflexivity**

According to Clancy (2013), a researcher's knowledge, interest, and behaviour may influence the research environment and data; therefore, critical reflective thinking, or reflexivity, is necessary throughout the entire research process. Reflexivity requires a researcher to be aware of their own assumptions, perspectives, and positionality to understand their role in relation to the study. The ability for the researcher to internally examine and acknowledge their presence on

the influence of findings will bring a more realistic interpretation of the phenomenon (Clancy, 2013).

My position in this study is a graduate student with a Bachelor's Degree in Dental Sciences. I am practicing part-time as a registered dental hygienist at a private dental clinic. I am in my mid-twenties of Asian people of Taiwanese descent who immigrated to Canada in the year 2000 with my family. I grew up in a middle class neighbourhood with mainly Caucasian residents, with English as my second language.

Only during my third year of undergraduate dental hygiene education had I learned about HIV/AIDS and the implications of oral health for PLWHA. I then enrolled in an intensive six weeks, six credit course, HIV/AIDS Prevention and Care, during the summer of 2016 where I along with other interdisciplinary students was introduced to the theoretical, clinical, and community components of the HIV epidemic. I also worked on a HIV-related research project, evaluating point-of-care HIV testing in dental hygiene education settings, as an undergraduate summer student where I gained fundamental qualitative research skills. I was also one of the fourth year dental hygiene students in the program who provided services at PLSBC from September to December 2016.

My past experience of being actively involved with qualitative research and the program, with a comprehensive knowledge of HIV and oral health is both beneficial and a disadvantage towards this study. I had a strong viewpoint about the program implementation at PLSBC as I was part of it. However, I needed to put my bias aside and look at my study from a neutral standpoint. My value on oral health was important throughout my education and as a practicing dental hygienist, yet this was often not the case for PLWHA. I had to constantly remind myself to disregard my position as a dental professional and instead view the program as a bystander.

This was not easy to do as my education and my practice in the private dental clinic emphasized oral health. I also understood how HIV stigma and discrimination occurs in health care setting due to personal stories and the community portion of my HIV Prevention and Care course, and how PLWHA often struggle through multiple challenges such as HIV disclosure. This knowledge helped me to identify and link their personal history in relation to utilizing oral health care.

Throughout data collection, I focused on being attentive to my participants' voice and continuously analyzed transcripts and themes during the process to ensure I was present. I reviewed my analysis constantly with my supervisor and throughout my writing. I had to correct and elaborate my explanations as I was using dental jargons and assumed the audience would understand the history and background of PLWHA as I had. Using interpretative phenomenology, I was able to reflect on Penchansky and Thomas' framework which guided me to relate my findings at a more in-depth level towards the concept of access and what it meant to my participants.

#### **2.4.2 Member checking**

Thomas (2017) described member checking as feedback obtained from participants to confirm, comment, or correct the researcher's findings or interpretations. The most common methods of member checking are sending the participant a complete copy of the transcript, a copy of emerging findings, a summary of the participant's case, or a copy of the research report, or all of the above (Thomas, 2017). Lincoln and Guba (1985) stated member checking is crucial to establish credibility or authenticity, yet many researchers argue there is no justification to how member checks enhance the quality of qualitative research (Barbour, 2001; Tong et al., 2007).

Despite contrasting views, I chose to utilize member checking as I wanted to verify my interpretations and ensure I had an accurate representation of perspectives or experiences (Thomas, 2017).

In my study, each member participant was offered a copy of a complete transcript or summary of preliminary interpretations of their interview. Only one member requested a complete transcript while four members requested a summary. One member responded back praising and confirming my summary of his interview. All members consented for follow-up contact to obtain any missed information. Two phone calls were made so that two participants could elaborate and clarify their responses in the interview, which were added on to my analysis. As I had a low response rate through electronic communication with no members correcting or adding to my transcript or analysis, I found discussing directly with members through the phone calls most helpful in member checking.

#### **2.4.3 Data saturation**

Saturation is used to decide when to stop sampling, often determined when no new codes, information, or themes emerge (Saunders et al., 2017). The view on saturation has been questioned as there is uncertainty and inconsistencies of how the concept of saturation is judged, measured, and achieved. Saunders et al. (2017) proposed researchers to adopt one of the four frameworks for better guidance on the use of saturation: theoretical saturation, inductive thematic saturation, a priori thematic saturation, and data saturation. I used data saturation where I identified repetition of the information I collected. By my eighth interview, I was starting to hear information that was redundant and anticipated. I conducted two further interviews and

when they yielded no further new knowledge to my study I believed I had reached data saturation.

#### **2.4.4 Triangulation**

Triangulation is used to test the value of the data through the convergence of findings from different sources (Carter et al., 2014), and to develop a comprehensive understanding of the phenomenon and enhanced analysis quality (Carter et al., 2014; Elliot and Timulak, 2005; Patton, 1999). The patient satisfaction forms summarized general feedback from members who utilized the program. The retrospective chart review provided a general description of my target population. Interviews obtained personal feedback and experiences of members who utilized the program, varying from those who were long-term to first time users. Finally with the focus group, staff and administration commented on how the program influenced their organization and the perceived impact that it had on access to oral health care for their members on a broader and deeper perspective.

## **Chapter 3: Results**

Findings from the 69 patient satisfaction questionnaires revealed the majority respondents were satisfied with the overall program. Findings from the retrospective dental chart review of 170 members provided a general overview of the target population, their oral health status and needs, and services delivered (Table 1-3, 6-8). Of the 170 members, 165 (97.1%) dental and periodontal assessments were completed; of the remaining five that had incomplete assessments, two had severe periodontitis, two had an insufficient CD4 count less than 200 cells/mm<sup>3</sup>, and one left early with assessments incomplete for the first appointment. The two members with severe periodontitis were referred to a dental clinic as this program was not equipped to address their needs and the two members with insufficient CD4 counts were referred to their general physician, and one member did not return with loss of contact.

### **3.1 Demographic characteristics**

Of the 170 members who utilized the program, 112 (65.9%) were between ages 45-65, 146 (85.9%) identified themselves as males, and the majority (72.8%) resided in the Downtown Vancouver area (Table 1). The majority (94.1%) reported to have a general physician. One hundred sixty-three (95.9%) had a CD4 count of over 200 cells/mm<sup>3</sup>, indicating a low risk for developing opportunistic infections, and 164 (96.5%) had an undetectable viral load of less than 50 copies/mL. Most members had one to three other (61.2%) health conditions in addition to HIV. The top three types of health conditions were reported as hepatitis A, B, or C (24.7%), respiratory diseases (20.0%) including asthma, pneumonia, tuberculosis, and chronic bronchitis, and mental illness (18.2%) including depression, anxiety, posttraumatic stress disorder, and bipolar disease. Other medical conditions most reported were various forms of arthritis (13.5%),

cancer (12.4%), gastrointestinal disease (11.8%), sexually transmitted diseases (11.1%), and kidney dysfunction (10.6%). The number of medications taken ranged from one to five (64.7%), with six (3.5%) taking no medications and 22 (12.9%) being on more than 10 medications (Table 2).

The majority (69.4%) reported they did not have a family dentist prior to utilizing the program. Of those 89 (52.9%) who had dental insurance, the majority (87.6%) were persons with disabilities (PWD) or persons with persistent multiple barriers (PPMB). Of the multiple chief concerns cited, an oral assessment (32.4%) or periodontal therapy (30.1%) was reported as the main reason for attending the clinic (Table 3).

### **3.2 Patient satisfaction surveys**

From September 2011 to December 2017, 69 patient satisfaction surveys were anonymously completed as shown in Table 4. Findings showed that 62 (89.9%) respondents reported that they ‘strongly agree’ to each of the statements with the exception of being satisfied with referrals. Most comments were positive, expressing members’ gratitude and satisfaction with the services provided. The majority (91.3%) of respondents answered ‘strongly agreed’ to satisfaction with equipment and supplies, and being comfortable during their care; the opposing six (8.7%) respondents provided written feedback with regards to having dental chairs, a suction, and more a comfortable set-up (Table 5). Five (7.2%) respondents did not report ‘strongly agree’ with students explaining the time of care, yet no comments were made to elaborate on their response. Four (5.8%) did not indicate if they were happy with their care and three (4.3) also did not respond if they would return to the program.

With regard to the referral process, respondents varied in their satisfaction; 51 (74%) reported that they were strongly satisfied, nine (13%) were neutral, one (1%) strongly disagreed, and eight (12%) did not respond to the question. Due to the lack of written feedback regarding the referral process, this was further probed in the interviews and the focus group to help to better understand satisfaction with this service.

### **3.3 Oral health status**

As shown in Table 6, of the 165 members who had complete oral assessments, 163 (98.8%) presented with at least some teeth while two (1.2%) were edentulous. The majority of participants (71.5%) were missing between one to eight teeth. Fifty-six (33.9%) had mobile teeth with a mean of  $1.4 \pm 3.1$ . Of the 85 (51.5%) that had suspected carious lesions, the majority (40.6%) had one to four lesions. The DMFT was found in 159 (96.4%) members, mean of  $13.3 \pm 6.2$ ; of the six members that had no DMFT, two were edentulous, and four were either healthy or their records were inaccurate/incomplete. No abscess or fistula was found. Twelve (7.3) descriptions of oral lesions were found with only one confirmed by biopsy as a focal epithelial hyperplasia.

Two (1.2%) had full dentures while 11 (6.7%) had partial dentures. Resin composite restorations were present in 119 (72.1%) members with 48 (29.0%) having one to four composite. Amalgam was the second most common type of restoration among 89 (53.9%) members, followed by 66 (40.0%) with porcelain-fused metal, and 30 (18.2%) with full gold crowns. Seven (4.2%) had sealants, 10 (6.0%) had temporary restorations, and five (3.0%) had at least one implant. Dry mouth was reported by 21 (12.7%) members. Finally, 136 (82.4%) presented with generalized gingivitis. Of the 80 (48.5%) with localized periodontitis, 33 (20.0%)

had mild, 34 (20.6%) moderate, and 13 (7.9%) severe forms of the disease; the two members who were referred for treatment of severe chronic periodontitis were not included.

### **3.4 Attendance**

Eight-nine members (52.3%) continued to attend the program. Of the 81 members who did not return to the program, students were unable to contact 63 (77.8%), nine (11.1%) found another dental home, four (4.9%) moved out of Vancouver, three (3.7%) could not commit to the operation times of the clinic, and two (2.5%) could not proceed with their care due to a CD4 count less than 200 cells/mm<sup>3</sup>. Of the 36 (21.1%) who did not complete their initial preventive dental care, 15 (41.7%) did not show for their appointment and 14 (38.9%) could not be contacted. Twenty-five (14.7%) had an incident and five (2.9%) had two incidents of not showing up for their appointment. Fifteen (8.8%) had cancelled their appointment once, two (1.2%) twice, and one (0.6%) three times (Table 7).

### **3.5 Services delivered**

Main preventive services delivered were periodontal therapy (78.8%), fluoride applications (73.5%), and oral hygiene instructions (78.8%). Few members received sealants (0.5%), specific examinations (1.2%), and a sports' guard (0.5%). Ninety-nine referrals (58.2%) were completed mainly due to suspected carious lesions or defective restorations (54.5%), fractured teeth (27.3%), and pain (14.1%). Only 24 (24.2%) proceeded with their referrals (Table 8).

The survey and chart review did not explain why members provided positive feedback, and why some discontinued while others returned to the program. To better assess the program, in-

depth exploration was needed from the members and the organization which was completed through personal interviews and a focus group.

### **3.6 Personal interviews and the focus group**

The qualitative analysis of the 10 personal interviews with members and one focus group with 12 staff and administration of PLSBC gave rise to 16 themes that were then arranged within Penchansky and Thomas' five dimensions of access: affordability, acceptability, accessibility, accommodation, and availability. Each theme was related to how it influenced each concept of access to oral health care for the members and the organization. One additional theme was not arranged under access as it related to how the program impacted the members individually. Characteristics of members and the positions of staff who participated in my study were briefly noted (Table 9 and 10).

#### **3.6.1 Affordability**

##### **3.6.1.1 Under and unemployment**

In 2015, the Canadian Institute for Health Information (CIHS) found approximately 6% of overall dental expenditures were public financed with the remaining 94% privately financed. Fifty-six percent of the general population pay for dental care through employment-based insurance and 38% directly out-of-pocket. Many of the members I interviewed relied on their employment or government funded dental insurances, but were unable to afford dentistry directly out-of-pocket.

Under and unemployment was a significant factor for some members who were struggling financially. As PLWHA may cope with the complex issues surrounding HIV such as

discrimination, illness, race, ethnicity, sexual orientation, and gender identity, they may not be able to work full-time and earn a stable income. For example, Members Three and Ten described how they had difficulty obtaining full-time employment due to the hardship of settling in Canada as immigrants in addition to the discrimination they have experienced from being HIV positive. Others had difficulty maintaining their employment such as Member Nine had to resign from their position in order to manage HIV and other medical conditions. Member Two had to take a medical leave, which turned into a formal resignation and retirement. Member Six and Ten were juggling various part-time jobs.

Some members also identified competing needs such as for food, shelter, and clothing that take priority over their dental care. Member Three and Nine in particular described their financial hardship and how the \$25 honorarium provided for participating in my study was needed to support their weekly grocery needs. In addition to these members who needed the participant honorarium to help with food purchases, Member Three shared, “*I have \$1,100 every month to pay for my rent, food, medications, and vitamins*” and went on to describe how difficult it can be to make ends meet living in this city. Member Eight also stated that “*because when you’re on a fixed income, you can barely make it through because you have to pay for everything else.*”

While dental care was deemed important, members stated they sought dental care delivered in private venues only when perceived as needed or under emergency circumstances. Members who were unable to afford dental care continually described how they often avoided dental care due to limited financial resources. For many of the participants that I spoke to, financial reasons were identified as a major barrier such as Member Two who said, “*Cost is what kept me away*

*from the dentist as many years as it had.”* Furthermore, those who lost employment found cost as a significant barrier to obtaining dental care:

*The only concern I had with dental care is that I had to pay for it, because I have been fully employed, but then I wasn’t covered with the dental plan. So I had to pay for it, the things out of my own pocket, these dental services. (Member One)*

It was clear that members have difficulty accessing oral health care due to cost, and one of the main reasons why the program was accessed and valued. The program was an opportunity for many members who were under-insured to receive some free preventive dental care with little impact to other life priorities.

### **3.6.1.2    Limits of public benefits**

Members who were unable to afford dental care directly out-of-pocket, often relied on publicly-funded dental benefits. To aid vulnerable and marginalized groups, the government of British Columbia Social Development and Social Innovation (2018a) offers public dental benefits to those who qualify. PLWHA may be eligible to receive financial assistance under PWD as they may have a severe physical impairment expected to continue for more than two years, or PPMB as they encounter long-term barriers to employment. The basic dental coverage for PWD and PPMB provides a maximum of \$1000 over two calendar years beginning on January first of every odd numbered year, and covers basic dental services including restorations, extractions, and some preventive services. Additional funding may also be provided for emergency services, dentures, partial dentures, denture replacements, or reline/rebase, and

crowns and bridgework if dentures are not permitted under specific circumstances (Government of BC, 2018b).

Unfortunately I heard that this amount of dental funding was often not enough to meet the dental care needed by members, especially when dental needs required were beyond what is covered as Staff G stated, “*If they had one of those emergency dental sessions, they probably wipe out their entire [dental coverage] allotment.*” This was elaborated on by Member Four:

*I've been on disability and we're limited to about one thousand every two years paid for by the government. When you start putting six cleanings over two years, that takes up more than half of your [dental benefits], and I was always needing fillings or bridges or a root canal.*

With the limited coverage of PWD and PPMB, “*having [the program] augments whatever service [members] are going to get based on coverage*” (Staff K). One of the more positive aspects of the preventive dental services that both members and staff discussed was that because the care was delivered free of charge, it allowed members to better maximize their dental benefits for other dental services.

### **3.6.2 Acceptability**

#### **3.6.2.1 Importance of trauma-informed care**

Throughout the member interviews, a prominent theme that recurred was the influence of trauma in their lives. Due to the intersectional characteristics of this population including vulnerability, medical comorbidities, mental illness, substance use, and low socioeconomic status, members were likely to have history of trauma. This highlighted the need for dental providers to

be trained in trauma-informed care (TIC). As staff G suggested, this type of preparation is essential for the health care providers, especially with regard to mitigating further trauma:

*Trauma-informed care teaches how some people have traumatic experiences in their lives that could easily be triggered by things we might take for granted...With the [members] that [PLSBC] have...we have to be better informed around trauma. So things like trust, safety, communicating well with your patient, those kinds of things are really important for people who are carrying trauma around.*

While many had described experiences of losing friends and loved ones to HIV, a variety of traumatic experiences and coping mechanisms were revealed which had a significant impact on their overall well-being as Member Two described:

*My PTSD was a build-up of a number of different things. My partner was killed in [an] accident, and I think that was the start of it, because I didn't deal with that very well. I got right involved with work. I worked as a community support worker... I had to go and get a drug dealer out of one of my client's apartment. And he called me up and needed help to get him. They had thrown his dog off the balcony, they had taken a knife to the throat of one of his friends, so I had to go and get him out...*

In addition to trauma related to work and personal life, multiple forms of dental trauma were described, specifically in relation to how it influenced the members' acceptability of a dental provider. Members wanted to feel safe in a dental setting because many had developed a high level of fear as Staff G explained:

*I was born with a cleft palate, so a lot of trauma with dentists, orthodontists... So then, to come out with HIV and telling that to my dentist, my dental hygienist, was layered in terms of challenges because of my childhood trauma. It was starting to be triggered.*

The onset of dental fear seemed to be related to individual vulnerability, traumatic dental experiences, or perceived threat, such as the experience of Member Two who avoided dental visits for a long time after his extraction; “[the dentist] had me back in a chair, he had his knee on my chest, he had both hands on the puller, and whipped my head back and forth trying to get this tooth out.”

Eight out of 10 members also described a traumatic experience related to the disclosure of HIV serostatus to their dental providers. Being HIV positive complicated the decision to disclose their HIV status to family, friends, partners, and health care providers. It seemed that the members’ HIV serostatus was not always accepted because there would be a display of discrimination from the dental provider as described by Member Five:

*It was just walking in and everybody was rosy... I fill out the form, and I checked off the HIV box. I don't know if they've ever had that box checked off before in front of them...it was like they were tripled glove. And she went into shock. I could see it in her eyes... It was almost a frightening experience. I was never afraid of dentists... but it was like they were terrified of me. They almost refused me.*

Each member had different reactions to how they deal with this type of behavior, from feeling discouraged and humiliated, “*I felt very disheartened. It was not a good feeling. Nobody likes to be rejected... but I was told, ‘You might bleed on my carpet’*” (Member Four), to

avoiding dental visits unless necessary such as Member Eight, who often struggled with disclosure:

*[I felt] mad, embarrassed... You just don't want to tell anybody for the fear of not getting looked after. But it also puts everybody at risk if they don't know...because if you tell [them] you don't get the service, and if you don't tell them you put them at risk. So I never went to the dentist.*

However, members seemed to have developed resilience and the ability to overcome the adverse effects following trauma, including negative dental experiences. Each member had a way to cope and adapt under challenging circumstances and toward trauma recovery. Member One briefly shared how another traumatic experience influenced his views to become more optimistic, “*I almost died a couple years ago, so I have a very different perspective... then it was HIV. I didn't know I was affected and if I was going live. So I see every day as a gift and blessing.*”

In contrast, Member Six who is Aboriginal had experienced numerous instances of mistreatment, violence, and cultural insensitivity over the years, described his strategy:

*I'm very upfront to the point and I let people know in any profession. If I'm there for specific reasons, you got to do those specific reasons. Don't ask for anything else. Do what I want. Do any more, you see the bad side of me.*

It was clear that members in their own way dealt with their trauma and one such coping mechanism was to seek care from dental providers who exhibited specific attributes in order to

prevent further traumatic dental experiences. This also included attending clinics such as this where HIV status was known, thus for most HIV disclosure was not required.

### **3.6.2.2 HIV knowledge and sensitivity**

Members who experienced past traumatic dental experiences seemed to emphasize the importance that dental providers should be knowledgeable in all aspects related to HIV, especially issues related to trauma and HIV-related stigma. Members discussed how they often seek health care providers who were knowledgeable about HIV as they were perceived to have a better understanding of the impact HIV diagnosis brings. They also thought that with these providers they were less likely to encounter discrimination. To prepare students for community-engaged learning, they were required to complete a six hour online trauma informed care course, a two hour violence and prevention course, and attend six three hour classroom sessions regarding management of vulnerable populations. With regard to PLWHA, students also completed a three hour online module about HIV and oral health that was supplemented by an in-class session with PLSBC staff who shared their lived experiences of HIV.

While staff and members recognized the program provided their members with access to preventive oral care and education, they also believed there to be a reciprocal opportunity as well to educate future dental providers. It was interesting that Members Five, Eight, and Nine in particular, identified the value of the opportunity to help students become more knowledgeable about HIV and the impact it has on one's life through attending the clinic. In fact, Member Five stated his primary reason for using the program is to educate the students about HIV, and to help them overcome any misconceptions and fear:

*This younger generation is learning... I keep coming back to that. Those are my biggest reasons for coming to this program. I feel all these dental hygienists should be exposed to HIV and what the protocol is, because obviously some people don't. It's one thing to say 'Oh we learned about it in school.' It's another thing to say, 'Yeah I actually worked on people with HIV and it's not a big issue.'*

Due to Member Five's negative dental experience, he had a strong sense of responsibility to help normalize the HIV epidemic and reduce the fear and stigma surrounding HIV. The program was an educational opportunity for some to help remove the fear students may have about PLWHA through interacting and learning cultural sensitivity early on in their practice as Member Eight believed:

*You're a service provider, and you're going to run across every single thing in the book. You can come in with all sorts of mindsets. If we educate more, put a little bit more emphasis on holistic care in spite of who or what you are... Then you'll see a big change in how people will be trained [at] hospitals, dental offices, or wherever they go.*

Members and staff agreed that it was not enough for students to only attend lectures and complete classroom assignments, readings, and modules. They also believed that students should learn beyond the hands-on clinical experience. Having the students volunteer at the organization was also an opportunity for them to undertake non-dental activities to help them gain a better understanding and appreciation for those living with HIV. These types of activities seemed to offer the opportunity for rapport building between the members and the students, and likely contributed to a positive relationship that encouraged members to access the available preventive

services. In this way, the program “*fulfills the secondary mandate of educating future providers and providing sensitivity training and cultural competency,*” (Staff E) and allowed students to apply their knowledge in a real practice setting:

*[Students are] learning what they would've never otherwise learned about people living with HIV... This has necessarily been carried over into their practices as they establish themselves, and thus contributes overtime a lessoning, alas not yet in evolution but certainly a lessoning of stigma associated with HIV.”* (Staff J)

Both groups indicated that the more educated a dental provider was about HIV, the more likely members felt comfortable and safe, and returned to that same dental provider.

### **3.6.2.3 Non-discriminatory attitude**

Comments about the way students treated members was another recurring theme, especially that students treated them “*like any other normal human being*” (Member Eight) with respect and a non-judgemental attitude. Members told me that students displayed characteristics such as compassion, earnestness, and genuine care towards them as Member One praised, “*I was always impressed with the courtesy, the manners, the grace with all the students and coordinators.*” As part of this community-engaged curriculum, students provide service through volunteer activities to gain a deeper understanding of the background of PLWHA. The students’ education and these activities may have allowed them to overcome HIV-related fear, prejudice, or misconceptions, thus developing empathy towards members that allowed them to have a non-discriminatory approach. Staff K noticed “*the students would interact with the members in the lounge, which I*

*thought was an amazing experience...Not only it educates the students, but the members. The young professionals are looking out for them... and are concerned about them. ”*

For some members, this type of non-threatening and caring attitude may have been different from what they have experienced previously with other dental professionals, especially if they felt discriminated against. Members often compared their past experience with their dental providers and the students, for instance:

*[At other dental clinics] I just feel that the focus wasn't on my comfort or consideration for me. It was all about making sure that [the dentist] could charge as much as he could and in the end, the work wasn't to high standard. I ended up having to get it repaired. (Member One)*

In contrast to this described perception, it seemed that members felt students made efforts to be respectful and caring, while at the same time providing them with valued professional care. Furthermore, members were grateful that students took time to interact with them personally which allowed them to feel welcome and safe using the program.

### **3.6.2.4 Informative and attentive**

Throughout the interviews, members also commented that the care students provided was “extremely informative, nice, and made [members] feel at ease” (Member Seven). For instance, students took the time to inform members of the assessments and procedures they were doing as Member Two noted, “[the student] was thorough, she was gentle, she talked me through it, ‘This is what I’m going to do, that’s what I’m going to do, this is why I’m going to do it.’” This approach and the attention that members receive appeared to increase their understanding of their

oral health, the implications of preventive dental services, and referrals if needed as Member Four described:

*I would always chat and I had learned a lot. I used the [program] as an educational experience and I'm always asking you guys questions. And about funny blue things on your lip or something and why are you so concerned about this.*

Some members also believed they received more comprehensive oral health education at the clinic which increased their understanding of the relationship between HIV and oral health as Member Nine described:

*I've learned a lot from the students much more than going to a regular dentist. All my life, you know, going to the dentist, 'You gotta floss, you gotta floss'... but you know the whole thing wrapping around your finger... just never worked for me. So I never flossed. When I came to use the program, they gave me all kinds of different tools to use... I didn't know I had like options of different kinds of tools I could use to do flossing... So now I floss on a daily basis because of the different tools they showed me. That was huge for me because that's helped out to maintain my gums.*

This type of interaction and exchange of knowledge between the members and students may have built a positive relationship and trust while encouraging members to be actively engaged in managing their oral health. It seemed members valued how students were providing oral health services in a personalized manner.

### **3.6.2.5    Oversight of care**

The final theme that emerged related to acceptability of the program was the perceived thoroughness and quality of the care provided. It was apparent that the instructor played a prominent role in ensuring consistent and competent services were delivered. Members perceived that because the instructor oversaw everything so that quality services and referrals were provided as Member Four stated, “*I appreciated having your professor come in and take a good look around and go over anything you folks have noted...And then let you guys know that you've missed a little spot.*” In addition, the interaction between the instructor to the students, then to the members also promoted comfort and safety as Member Five observed:

*[The instructor] makes [students] feel as much comfortable as I feel from them so it's sort of like a waterfall. It comes from the top down. Her interaction with [the students] is great. Her communication skill with them is great therefore, they passed that on to me. The way they treat me is great and I can see it through her through them to me so it's consistent across the board.*

Although every semester students rotated to different community sites and members saw a new group of students almost every appointment, it was important that the standard of care remained the same. Informing members how the program operated allowed members to understand that “*they get the same level of care because the [instructor] is keeping an eye on what's going on and bridging across what's different across the semesters*” (Staff L). However, Staff B was concerned that not all members were aware of where the students are in their training and suggested:

*It might be good education demystifying the mind what the student is, because I*

*don't necessarily know that information is provided. Where are they in their training, how long, what have [the students] done to get here?*

Further communication and clarification of the program may be needed to better inform members regarding the clinic at PLBC such as the set-up, appointment time, student and instructor providers, preventive dental care, and referrals delivered, particularly for new patients unfamiliar with the program.

### **3.6.3 Accessibility**

#### **3.6.3.1 Location and service convenience**

The PLSBC facility was originally located in Vancouver's central business district, known as Downtown Vancouver. From January 2015 to August 2017, the facility was under construction and moved to the Downtown Eastside of Vancouver (DTES), a community known to struggle with issues of drug use, crime, poverty, mental illness, homelessness, and unemployment (City of Vancouver, 2018). PLSBC was relocated back to Downtown Vancouver in September 2017. The 10 members interviewed had lower to middle income or were retired, and commuted around the lower mainland of BC by public transportation. Members expressed the increased convenience of traveling to the Downtown Vancouver location compared to the DTES in particular because of the transit options and as Member Seven said, "*it's just that [the DTES], it's kind of out of the way, it's off. [Downtown Vancouver] is pretty direct with your sky train then you take a bus. Whereas [the DTES], sky trains are not that close.*" Even Member Five who had his own vehicle, expressed his preference of utilizing Vancouver's public transit to avoid parking fees and the search for a parking spot.

In addition to greater transit options, more service organizations are located in Downtown Vancouver, specifically HIV-related services such as housing at McLaren Housing Society of British Columbia, the immunodeficiency clinic at St. Paul's Hospital, and health programs and nursing care at the Dr. Peter AIDS Foundation. Staff B believed the Downtown Vancouver location allowed members to conveniently access a variety of health and social services that are in close proximity with each other, and that the Downtown Vancouver location “*is more in a service corridor. Members can go to St. Paul’s Hospitals, mental health, a doctor’s appointments at Spectrum, and they’re on the bus line. Everything is close to here.*” Furthermore, a variety of services offered at PLSBC increased the convenience of services accessible within the organization:

*[PLSBC is a] one stop shop for our members... The more services we have, the better for our members. It makes it convenient... I've heard that time after time from members, 'I'm great, I'm going to Positive Living BC, I can get a haircut, I can go do my taxes, I can go do dental work, I can do all sorts of other programs.'*

(Staff K)

With services immersed in Downtown Vancouver, members also sought oral health care service that was close to their residency. Unless a specific dental professional or practice was recommended, members chose their initial dental clinic based on proximity. The travel distance was emphasized as an important consideration, with the Downtown Vancouver location more favourable to members and staff. Member Nine described the inconvenience of the program when it was relocated to the DTES:

*[The DTES] was not convenient at all. I didn't like going over there. It was just out*

*of the way for me. [Downtown Vancouver] is much better because it is walking distance from my place, about fifteen minutes. It's extremely convenient. It just makes it much more doable and accessible.*

The transit options to commute to a dental clinic, accessibility of other services, and travel distance each influenced members to access dental care. It was not surprising to hear that the more convenient the location, the more likely members are to make efforts to seek oral health care. Similarly, with the clinic at PLSBC which was located close to where members live appeared to make members more likely to access the program.

### **3.6.3.2 Socioeconomic context of the neighborhood**

In addition to location convenience, acceptability was also influenced by the neighbourhood itself. Since the 1950's, the DTES community had declined due to closures of the interurban rail line, North Shore ferries, manufacturing operations, and lack of tourist traffic. Hotels were converted into single room occupancy housing affordable for low-income residents, many of whom use substances, were previously institutionalized, or mentally unstable. With close proximity to the Vancouver port, drug activities eventually flourished in the neighbourhood and market. Since then, the DTES has shifted to a community plagued by homelessness, sex work, crack and cocaine, crystal methamphetamine, mental illness, and addiction (City of Vancouver, 2018; Dobson, 2014). The surrounding environment of the DTES seemed to create a sense of uneasiness due to perceived lack of safety, protection, and privacy for members coming to PLSBC. This was the case especially for members who were accustomed to the Downtown

Vancouver environment, but then had to access the program at the DTES as Member Five described:

*You could hear some people getting raped sometimes. You could hear the people come in and off the streets. It's just the situation in that neighborhood. You're not involved, but you're still subjected to it.*

Despite the lack of feeling safe in the DTES, staff and members described some benefits to the location, particularly in regard to the different population living with HIV that they were now able to reach as Staff K recalled, *"I remember in the DTES, we were able to reach a lot more individuals that we would never see in this neck of the woods. Basically people in DTES don't leave it. It's their area."* Staff presumed that the DTES residents may not feel comfortable coming to a facility located in Downtown Vancouver where it is a busier commercial area comprised of people who may be of higher social status. This assumption seemed reasonable as similarly when their location was in the DTES, members who frequented the Downtown Vancouver location did not feel as safe when leaving their comfort zone. However, another explanation could be due to the short period of time that PLSBC was located in the DTES, it may not have permitted the organization to build a strong enough relationship with those residents:

*When we're at the [DTES], a lot of people may have availed themselves for services... but they don't think we were there long enough for them to get connected to us. Because they think there's a trust factor involved, and a lot of people think we're already seeing people who they've felt they wanted to see, and they're connected to services they wanted to see... Anyways I think [the DTES] had a greater decline. [At Downtown Vancouver], I'm seeing more people coming in.*

*More volunteers, more people in general. (Staff B)*

The program may also not have been able to deliver consistent oral health care or stayed long enough for members from the DTES to become more familiar with the program. As well, the DTES residents would have to access the program when located back at Downtown Vancouver, which may not be as convenient or comfortable for them.

It is unknown how the neighbourhood and location differences affected members living in the DTES, as only Member Six lived in that area of the city. Member Six was also a volunteer at PLSBC and remained active with the organization at both locations, and was able to adapt to the difference between the neighbourhoods. Members who were not as engaged with PLSBC may have chosen to discontinue services and support with the organization and with the program. However, the seven members who are Downtown Vancouver residents commented that although they did not feel as safe in the DTES, they perceived the program was worthwhile and made efforts to endure the neighbourhood in order to receive their care.

### **3.6.4 Accommodation**

#### **3.6.4.1 Self-disclosure of HIV status**

The clinic was able to reach out to the PLWHA community due to the integration of the program at PLSBC. Due to the location of the dental program and the requirement that members of the organization be HIV positive, disclosure of serostatus was eliminated. This emerged as an important factor in choosing to access oral care as several members described the ease of not having to disclose themselves, that “[they] don’t have to be the ones saying it” (Member Eight) and “it’s one less thing to worry about” (Member Four). The program at PLSBC removed the

barrier of HIV discrimination and eliminated the members' struggle and decision to disclose their status.

*Of course the whole idea is that you don't have to disclose here. It's sort of given for our members, that everyone here is HIV positive. There isn't that one last hurdle to get over. It's a lot lower barrier to access the service. So I think that's wonderful. I've done community dental clinics where I still have to have that discussion.* (Staff K)

As Staff D stated, PLSBC strived to “*demonstrate the ability to offer services [that are] non-judgemental, stigma free... [and] safe to access*” so members may feel more comfortable and safe at the organization. Member Ten reiterated the stigma-free environment at PLSBC, “*I would prefer to stay [at the program] because I know I'm not going to be discriminated and be looked at as a freak.*” It appeared that members preferred HIV specific facilities as staff and practitioners are perceived to be more knowledgeable and aware of issues surrounding HIV. Consequently, the collaboration with PLSBC may have been one of the largest facilitators to access to the dental services provided by this program as it may have been more approachable and non-stigmatizing than other clinics. Accessing services at non-HIV facilities may put members at a higher risk of experiencing discrimination as Member Eight experienced from his dental history:

*I'm terrified of the dental office, and that's based on my experience. Here, because I also volunteer here... I feel more comfortable here, being in a non-judgemental space. Going to a dental office, I won't know what I'm going up against.*

### **3.6.4.2 Duration of appointment**

Each appointment at the clinic can take up to two hours for students to complete their service delivery from preventive dental care to oral health education to referrals. For new patients that have not had visited a dental professional for a period of time or required extensive periodontal therapy, the time allotted may take up to two visits. It was anticipated that this two hour time period would be a detriment to the program. Yet, it seemed the extended appointment time permitted members to feel more at ease and relaxed as Staff L commented:

*Traditionally, students take a lot longer to clean someone's teeth... A lot of our [members] like that the students take longer because it gives them a couple of hours to lay down and relax and have someone focus on caring for them and that's something I hadn't thought of before, but we actually have that feedback a lot.*

Members believed the two hour appointment time allowed students to dedicate more time to personal attention, interaction, and education with them, characteristics which were favoured as “*greater patience is offered to [members] ...and they're not feeling rushed or on the clock*” (Staff D). Some members also commented on the perceived thoroughness committed to their care due to more time, such as Member seven who expressed:

*You've got two hours so [the students] do a lot... they're checking your pulse... checking for bumps...She's found something on the back of my ear that could potentially be a problem, or maybe not, but alerted me to another health issue that might be happening.*

The positive feedback of a longer appointment indicated that this may be a more appropriate approach for community-based programs such as this one, considering this patient pool may have experienced various life challenges and trauma, and appreciated the greater amount of time dedicated to their care and interaction.

### **3.6.4.3 Facility design**

When the program was first established in 2011, PLSBC had carpeting throughout their organization that precluded the use of power equipment due to the aerosol production and inability to maintain infection control. Space was also quite limited and needed to be shared between different practitioners who offered services at PLSBC. For these reasons manual periodontal therapy was provided on massage tables that were also being utilized at other times by massage therapists. The clinic continued to use the massage tables because the majority of members did not express great dissatisfaction or discomfort with them, but instead described the experience as varying from comfortable to stiff to strange. As Member Four stated, even now that we are in the new building “*we are still on massage benches here with your head tipped over. That's okay. I don't mind that at all. In fact, it's kind of restful.*”

Member Two found the massage chairs different and ergonomically incorrect for the students:

*It was just unusual. Comfort and non-comfort, it didn't affect me either way.*

*Laying down was interesting. It wasn't good or bad. [I am] accustomed to be raised and reclined, but in this case, the hygienists had to adjust themselves as opposed to adjusting me.*

Members who did not find comfort with the massage chairs however came to moderate their view as Member Eight said, “*it would be nice to have a couple of dental chairs instead of beds... but the space is fine and it is what it is.*” Similar to various responses received with the massage chairs, some members noted the benefits to having power equipment available for better comfort and ease of their appointment such as Member Seven who stated, “*you don't have the rinsing spit sink you know...I did have water, but I did need to spit it out into another cup. So that's just one difference, but I don't mind the little hand tools.*” While the program did not have power equipment or dental chairs, members showed understanding that the program was doing the best under the circumstances:

*[PLSBC] doesn't really have room to set up specifically for the students to be fully equipped, so I'm not coming in and expecting to have the latest of anything. I'm expecting manual and that's because you don't have a room set up for dental hygiene. So I'm fully aware of that and it's fine with me. (Member Eight)*

Furthermore, it appeared this type of facility and equipment set-up created a non-intimidating, quiet environment that allowed members to feel more relaxed as compared to the high-tech equipment that produce a “*functioning noise... and made [members] more alert*” (Member Seven). Many members were in favour of this casual setting without dental equipment because “[members] have [their] own intimidation of a sterilized dental office with all those drill sounds and all the compressors going” (Staff E). Furthermore, as this patient pool is more likely to have experienced trauma, removing triggers such as the noise from power dental equipment, and creating a quieter comfortable setting may have been beneficial in managing PLWHA in this type of setting.

### **3.6.5 Availability**

#### **3.6.5.1 Addressing immediate dental needs**

As part of the students' education, they were required to learn how to manage a community-based program. Scheduling appointments allowed students to understand the administration of a practice so that they can learn to become self-sufficient in their future professional career.

Although both students and members were learning how to effectively communicate with each other, some members found the appointment system a negative aspect of the program. The lack of immediate contact and availability was not meeting the needs of the members who had to call a designated phone number to contact the students. When the program was not operating, members were required to leave messages through the answering machine for students to contact as Staff D described:

*Some members have commented that they never get to speak directly to an individual whenever they call. So it's usually a follow-up call. It's very rare [members and the students] make first contact when dialing the dental clinic. It's usually a returned call within a certain amount of time. It's usually not an extraordinary amount of time that lapses, but it's not the 'I'm picking up the phone and I'm talking to somebody right away.'*

In addition, the program only operated during regular PLSBC hours from ten in the morning until four in the afternoon on Wednesdays during the school year from September to early April. Several appointments were also arranged to serve members during the summer. Due to the program's operational time and appointment system, immediate dental needs from members were often not possible. Further information or inquiries from members cannot be

responded to until students have direct contact with the member as one of the peer navigators at PLSBC, Staff C noted:

*In the case when it's like, 'I have a dental appointment I'd like to make, but I actually have a problem right now. I need to get in touch with a dentist.' That is probably the time when it's most frustrating to [members].*

Another setback with regard to the program's hours of operation was that members had to adjust their schedule and book in advance to receive their services in a timely manner. Although Wednesday hours of operation worked well for members who are retired, unemployed, or volunteered on Wednesdays, the program is not available for those who work on that one day and need the income: "*If I book it far enough, [my appointment] would fit in my schedule... But there are people who work ...and they would have to take time off. It can be costly because they have to take time off*" (Member Eight).

As a way to remedy this problem, staff suggested the time being served to patients be expanded to include some weekend or evening appointments and consider a more enhanced summer program. While the days and times did not suit all of those I spoke with, the program's flexibility and the ability to drop-in for appointments or to inquire about resources prior to booking their appointment, was perceived as a positive aspect of the clinic such as Member Four who stated, "*the program has an open door. So if I need to change something, I can always come down and knock on their door.*" Members also noted a more consistent and organized process of booking their appointment as Member Nine described:

*[The students] have improved in following up with phone calls, getting a hold of people, and reminding me... It is much better than it was in the past. In the past, it*

*was kind of hit and miss and was hard reaching someone. It was just kind of all over the place but I've noticed since I've been with the program, [the phone calls] has tightened up.*

It was clear that this program is readily available to meet the dental needs of members who are active within PLSBC and willing to work with how the program was set-up according to the students' curriculum. This program did not seem to have the capacity to serve members who required urgent dental care and those unable to commit to program operation hours and dates.

### **3.6.5.2 Referrals**

To address the dental treatment needs of the members, the program completed referrals for members to regular and reduced cost dental clinics in the Vancouver area when dental examinations, x-rays, and restorative care were indicated. The survey reported some lack of satisfaction with the referrals and the retrospective chart review found a lack of follow-up of referrals by students. No significant findings emerged upon the referral process of the program to explain responses from the satisfaction survey and attendance of referrals. The personal interviews revealed some members already had a dental office they visit regularly, some perceived regular dental care was unnecessary, and some could not afford further dental care. Only Member Four found a permanent dental home at the UBC Dentistry Specialty Programs as per his referral:

*I'm kind of spoiled now. I have a prosthodontist, I have an endodontist, and I have a periodontist. So, I have specialists and I kind of like that rather than a do-it-all, jack-of-all-trades regular dentist.*

Referrals were critical to increasing dental care access as members may have difficulty navigating the private dental system themselves. Before the program was implemented, Members Four and Nine indicated that in their search for dental care, they inquired at PLSBC for recommendations. The peer navigation and communications department at the society served to help members search for services such as housing, employment, and government funding. Staff G, a peer navigator commented before the program, “*many [members] came to [the organization] asking how [staff] can look after these things. Because dental is one of the hardest things to get covered. Even with people on those benefits, it’s incredibly limited.*” With the referrals provided at the program, staff noted it had helped increase dental resources for the organization and helped members navigate the dental system.

### **3.6.5.3 Community dental clinic at PLSBC**

With the increasing awareness of the importance of oral health, the PLSBC opened a community dental clinic within their organization in January 2018. Staff expressed that the groundwork and longevity of the preventive dental program was key to requesting funds from the BC Ministry of Health:

*It was the letters of support, it was the history of dental hygiene work at [PLSBC] ... that grounded the proposal, and gave us credibility. That all came to fruition when we did the dental clinic because we recruited a lot of people through UBC Dental to sit on the advisory council. It helped us develop [our dental clinic] and put it in place. (Staff J)*

While the new full-service dental clinic provided a needed referral source for the program which continues to operate, having two dental programs running in the same organization did create an expected problem as members were uncertain whether to visit the dental clinic or the program with the overlap of preventive dental services offered at both:

*I was curious..., because we have dental hygiene, and because we have a dental clinic, how members can sort of differentiate, ‘Where should I go? Should I make an appointment in dental hygiene and keep going there, or should I sign up to see a dentist at the dental clinic?’* (Staff B)

This community dental clinic was not specific for their members, but provided “underserved individuals” with dental care at a reduced fee (PLSBC, 2018). This clinic differed from the program in that it was not free of cost and it did not automatically self-disclose members’ HIV status, both found to be facilitators in the program. However, the new dental clinic may have allowed for access to oral health care that is more convenient and accessible because it is available and associated with the same organization, such as Member Nine who assumed:

*I don’t know if they’re nice, friendly, or professional. I’m thinking they should be due to the fact that they’re in the building in their part of the Positive Living Society. So I’m sure they would be educated and everything.*

### **3.6.6 Impact to members personally**

Members and staff often wanted to discuss how the program seemed to have influenced members individually in regard to their self-confidence and personal empowerment. With continued utilization of the clinic, members described how they gained a better understanding

and “*more in depth the importance of oral health and how it can affect different health issues*” (Member Nine). Members and staff recognized the impact of oral health not only for physical health, but also related to self-confidence such as when Member Three told me that oral health is “*important for your health when you’re eating, when you’re smiling, and when you’re talking with people*”. Staff G indicated access to the program may have also provided members the opportunity to maintain their dentition and positively influence their appearance:

*For people that have to get their teeth extracted and go to dentures and it’s really hard on the individual. It’s huge. I mean image, just how you feel about yourself... and when you see people in dental pain, it’s not a fun thing.... When you see people to the point where all of their teeth have to come out, it really means somewhere in our system, we really fall aside. So to be able to offer this [program] to people who still have their own teeth that can be salvaged and fixed, it’s a huge difference.*

These suggested positive outcomes of the program to members’ oral health, overall health, and personal empowerment may have impacted their willingness to continue to utilize the program. Staff B perceived the program to be of benefit for members who are towards recovery and self-care, because “*it’s very emotional for quite a few of them when they’re going through the process of getting help...For the first time it got them on the road to the possibility of getting a new chance, a new life, new experience.*” This program also appeared to have encouraged members to become more involved with their community at PLSBC, potentially helping members to achieve a healthier lifestyle physically, mentally, and emotionally:

*The dental hygiene clinic has acted as kind of a lost leader, to get [PLWHA] in the door; to those who have not otherwise set foot, in an AIDS organization... but once*

*here, they're slowly becoming enmeshed in what the rest of what [PLSBC] has to offer.* (Staff J)

## **Chapter 4: Discussion**

This study aimed to describe the population of PLWHA utilizing a community-based preventive dental program, their satisfaction with the services, and how it influenced their access to dental care. The program made dental care more affordable because members in general were underinsured, underemployed, and had other basic life necessities that competed with their dental needs. Due to the influence of trauma, members appreciated how the students and the clinic setting allowed them to feel safe and comfortable. The program collaboration with PLSBC also supported members with various health services and resources to manage their overall health within a convenient location, and removed HIV-related stigma. Members also valued the opportunity to educate future dental professionals about cultural safety and HIV sensitivity to help reduce stigmatization. Overall, members were more motivated to return for preventive services if they perceived oral health as important and sought to maintain regular care. However, the members' other dental treatment needs may not have been met due to the possibility of becoming lost in care during the referral process which can also be influenced by the various dimensions of access related to the referred dental clinic.

### **4.1 Financial ability and resources**

In Canada, the majority of oral health services are delivered through the private sector, affecting vulnerable populations that not only struggle socially and economically, but suffer the highest level of oral health problems (CAHS, 2014). Leach and Birch (2008) described Canada's oral health system as ascribing to the "inverse care law" because those who need dental care the most receive the least, while those who need dental care the least receive the most. The inequity

of oral health care is impacted mainly by income distribution and dental insurance (Allin, 2008; Bhatti et al., 2007; Health Canada, 2010; Thompson et al., 2014).

The majority of the members that I interviewed were often under- or unemployed which caused them to struggle financially to address their dental needs under Canada's oral health system. Members who were under- or uninsured for oral health care services also faced difficulties meeting their dental needs. Approximately half of the members had some type of dental insurance, usually PWD or PPMB. However, the coverage limits of these benefits prevented members from affording all their needed dental care. Many expressed that the amount of coverage was insufficient to fully cover costs when more than basic dental services were needed. Members also stated that they would avoid dental visits if they had competing financial priorities related to medical co-morbidities, substance use, or basic life necessities. This was consistent to Jessani et al. (2019) who found that more than half of the PLWHA participants faced challenges associated with access to food, housing, transportation, clothing, and dental coverage. Additionally, Muirhead et al. (2009) identified that poor working Canadians struggle with food insecurities which competed with paying for their dental care. It appeared that members had to first be managing multiple aspects of their lives sufficiently before they could attend to their oral health care needs.

Due to the lack of financial stability and resources, many members could not afford dental care. The program addressed the members' financial challenges by offering services free of charge where they were able to receive preventive services without paying out-of-pocket or utilizing their limited dental benefits. Since members did not have to allocate any of their dental benefits towards the program's preventive services, it allowed them to utilize their coverage to receive other types of dental services. This program also allowed them to receive preventive

dental care without affecting their life priorities. Furthermore, if members could not access other dental venues due to cost, this program may have been their only opportunity to receive some type of dental care. As members were significantly influenced by the cost of oral health services, the affordability of the services offered at the clinic was one of the main reasons members initially came to the clinic and continue to do so.

## **4.2 Influence of trauma**

Trauma is “an event, set of events, or a circumstance that is experienced to be physically or emotionally harmful and result in lasting adverse effects on the individual’s well-being” (Substance Abuse and Mental Health Services Administration [SAMHSA], 2012). A trauma that is re-triggered may induce a reaction of fear, anxiety, helplessness, or horror (Raja et al., 2014). Complicated histories of trauma are especially common among PLWHA and are often associated with substance abuse, sexual abuse, mental health, stigma, poverty, ethnicity, and sexual orientation (Sales et al., 2016).

Many members discussed trauma in their lives related to adverse childhood or adulthood experiences, receiving their HIV diagnosis, disclosing their HIV status, and negative behaviour from health and dental professionals who were aware of their HIV status. Each member described how their traumatic dental experience was likely caused by HIV discrimination and affected how they accessed dental care. This came as no surprise as perceived discrimination and HIV-related stigma are often associated with lower access and usage of health and social services. (Reuda et al. 2016; Schuster et al. 2005).

Members coped with the perceived discrimination in various ways, such as the development of dental fear, avoidance of dental visits, or confrontation to the perceived negative attitude or

behaviour. Due to the influence of individualized vulnerability and trauma that played a significant role within the lives of members, they required a trauma-informed approach to care in order to promote safety, trust, and empowerment. Similar to others (Donnelly et al, 2016), I found that the members seek dental clinics and providers that allow them to feel safe and accepted regardless of their HIV serostatus to prevent further discrimination and trauma. The past dental experiences of members played a role in the acceptability of this program because they appreciated specific attributes related to the providers, the facility, and the way services are delivered. Student provider characteristics and the clinic design seemed to have also played a role in creating a sense of protection, safety, and comfort for the members while the clinic offered within PLSBC provided for a stigma-free environment, convenient access, and various resources.

#### **4.2.1 Provider characteristics**

It appeared the trauma-informed care (TIC) education incorporated in the students' curriculum may have helped students understand the role of trauma in members' lives. TIC training is recommended for all HIV care related staff, clinicians, and providers so that they receive information related to creating safe clinic environments, routine universal trauma screening, responses to disclosure of trauma, and resources for referrals and therapy (LeGrand et al., 2015). TIC encompasses informed values of safety, trustworthiness, empowerment, respect, and resiliency to encourage healing and to avoid trauma triggers (Machtinger et al., 2015). Similarly, Raja et al. (2014) propose a TIC pyramid with the basis of strong behavioural and communication skills to specifically educate dental students and guide dentists working with traumatized patients.

Members believed students displayed traits of TIC in that they were informative, non-judgemental, caring, and respectful which made them feel welcome and safe. The non-dental activities that students participated in at PLBC, the longer appointments, and ongoing patient education may have also enhanced communication between the students and members. The interaction between the patient and provider is crucial in developing trust, rapport, and empathy (Corah et al., 1988; Mallison et al., 2007; Tobias et al., 2012). Although members were likely to interact with a different student each time they came to the clinic the instructor remained the same providing continuity and an ongoing opportunity to connect with members and establish trust. This consistency appeared to be particularly important for the program since others have found that it is more likely for patients to actively engage and return for care when trust is established (Bedos et al., 2003; Graham et al., 2004; Mofidi and Gambrell, 2009; Parish et al., 2015). Therefore, the ongoing interaction and trust developed between members, associated personnel of the organization, and the students, instructor, and coordinator of the program may have encouraged members to utilize the clinic. The personal characteristics, attitudes, and behaviour of the students and the instructor seemed to be well accepted by members and had an influence on their desire to access the clinic.

#### **4.2.2 Clinic setting**

PLWHA who have traumatic dental experiences often develop dental fear or anxiety (Abrahamsson et al, 2002; Beaton et al., 2014), a significant factor that contributes to avoiding dental visits (Appukuttan 2016; Jessani et al., 2019). One of the triggers that can cause the onset of dental anxiety is sensory, such as the unpleasant sound of dental drills, sensation of high-frequency vibrations, or sight of anaesthetic needles (Hmud and Walsh, 2009; Yamada et al.,

2006). Patients may also feel a loss of control and helplessness, and a threat in their autonomy when in the dental chair (Abrahamsson et al., 2002). Therefore, the reduction of dental stimuli, triggers, and noise, as well as the atypical setting and design of the clinic may have established a non-threatening, quiet, and casual environment. While some members acknowledged that the equipment and massage chairs could be updated, they felt however, that the clinic had promoted comfort and relaxation. The setting of the clinic seemed to have complied with the standards of TIC to help members feel safe while avoiding trauma triggers, and to have influenced the acceptability and accommodation dimensions of access.

#### **4.2.3 Collaboration with PLSBC**

PLWHA are more inclined to utilize services that are recommended to them by their physician or peers, which are often HIV-specific clinics or facilities that diminish the risk of discrimination (Brondani et al., 2012; Cunningham et al., 2007; Donnelly et al., 2016). The collaboration with PLSBC was essential in reaching PLWHA who were registered and familiar with the organization. As PLSBC is comprised of staff and practitioners who understand the complex issues surrounding HIV stigma and disclosure, members may have felt safer and more comfortable utilizing services at the organization.

As the clinic was only available to members, there was no need for HIV disclosure when they attended the program. Although members did need to discuss with students and faculty specifics about their HIV status, such as viral load, CD4 count, and medications to ensure safe delivery of care, the need for disclosure was eliminated and perceived discrimination and stigma eliminated. Ultimately the location of the clinic within PLSBC enabled emotionally safe access to preventive dental services and accommodated the unique needs of PLWHA.

PLSBC also offered other types of services for their members to support their general well-being and having dental services included in the same place enhanced their availability.

Multidisciplinary clinics have been described as an innovative strategy for establishing a medical home with access to multiple health services for PLWHA that can enhance oral and overall health, especially for those with multiple chronic conditions (Bachman et al., 2012; Cargill, 2016). In addition, del Rio et al. (2016) recommend such clinics also address structural barriers and support hard-to-reach PLWHA in relation to poverty, unemployment, food insecurity, unstable housing, mental illness, and substance use. PLSBC addressed these barriers by offering various resources and other health services such as prison outreach, treatment outreach, and community health funds. Members who were active within the organization, particularly volunteers, valued managing their lifestyles and health. It seemed that PLSBC offered sufficient resources to meet the overall needs of members, non-medical and medical, to support their overall health which may have further encouraged members to utilize the clinic.

Finally, the accessibility of dental services depends on the patient's ability to reach the facility, taking into account transportation, resources, and travel time (Horner and Mascarenhas, 2009; Penchansky and Thomas, 1981). Roughly three-quarters of the members lived in the Downtown Vancouver area where PLSBC was located, followed by a quarter who lived outside the city, and a few who resided in the DTES. It was convenient for the majority of members to travel to the program due to various transit options, the proximity to their home, and easy access to other services that were saturated in the area. In contrast, transportation and services were limited at the DTES and may have caused difficulties for members to access in an uncomfortable neighbourhood.

### **4.3 Training future professionals**

As stigma and discrimination continue to exist as a persistent barrier to care among PLWHA (Chambers et al., 2015; Donnelly et al., 2016; Kinsler et al., 2007), some members took the opportunity to help reduce HIV stigma among future dental hygienists by attending the clinic. The ability to educate students and faculty about their lived experience of HIV and dental care was described as empowering and for some one of the main reasons they attended the clinic. Members and staff agreed that students should not only learn from textbooks but experience hands-on clinical encounters as well as social interactions with members in order to grasp a comprehensive understanding of living with HIV to mitigate misperceptions, stereotypes, prejudice, and discrimination. This is in line with other academic curriculums that provide HIV education and training for medical, dental, or dental hygiene students in order to improve cultural competency with an increased compassion and empathy towards providing patient-centred care for PLWHA (Jaworsky et al., 2017; Rogers et al., 2011; Zaninovic et al., 2013).

### **4.4 Self-perceived oral health**

PLWHA who are motivated to manage their CD4 and viral load counts tend to believe oral health is important (Rajabiun et al. 2012). This is consistent to the dental chart findings that revealed the majority of members were managing their health successfully with sufficient CD4 counts, an undetectable viral load, and the presence of an existing physician. Members who valued the program also seemed to understand the implications of oral health on their general well-being, thus returning to the program. This suggests that members who continue to utilize the clinic had basic health literacy and were proficiently and actively managing their health.

Personal appearance may have also been a driver for utilizing the clinic for members who value this aspect. Oral health affects the personal appearance, overall self-esteem, and social isolation (Rajabiun et al. 2012). People on social assistance emphasize the importance of appearance as it has a significant impact on their self-confidence, social interactions, and employment (Bedos et al., 2009). The oral health-related quality of life (ORHQoL) reinforces the concept that oral health is comprised of biological, social, psychological, and cultural factors, and the appearance of the face and dentition may influence the well-being of the patient (Sischo and Broder, 2011). My findings indicate that the members' values on oral health, overall health, and their appearance may motivate or hinder them to attend the program and potentially other types of dental care.

#### **4.5 Dental treatment needs**

Previous studies have reported that roughly half of their participants who are living with HIV have unmet dental treatment needs (Jeanty et al., 2012; Jessani et al, 2019; Marcus et al., 2005). Although the majority of members who I interviewed seemed to express little need for emergency and restorative dental care, the oral health status from the dental chart survey revealed most members presented with composite and amalgam restorations. Some members also had crowns, dental prostheses, or implants. This indicated that members have received dental treatment prior to or during the program. Furthermore, approximately half of the members received a referral to address restorative dental needs for suspected carious lesions, defective restorations, broken teeth, and pain, indicating that there were dental treatment needs among this population. However, only a quarter of this group followed through with their referral for reasons unknown.

The program did not have the availability to offer comprehensive dental care, yet members seemed satisfied to receive the care offered and the ability to receive a referral to address their other needs. Students would have performed an oral assessment and provided a referral to a dental clinic for the member. However, I found, members may not have attended the referral due to the influence of the various dimensions of access. Members would be required to approach an unfamiliar dental clinic and dental professional, with the perceived possibility of experiencing discrimination. Members would also be influenced by multiple factors such as their lack of financial resources, past experiences, trauma, stigma, perceived oral health need, or location and convenience of the clinic. Although this was taken into consideration and referrals were provided for clinics that were publicly-funded and known to offer trauma-informed and patient-centered care, other circumstances may have prevented them from following through. Thus, members may have been lost during the referral care pathway due to the interrelated dimensions of access and lack of priority.

## **Chapter 5: Conclusion**

### **5.1 Implications and recommendations**

This study utilized Penchansky and Thomas' framework to describe how a community-based preventive care program influenced access to oral health care for PLWHA. My findings highlight some key implications for dental providers as well as recommendations for future research.

First of all my results indicate that there is a need for dental providers to be mindful of the socioeconomic status of PLWHA as well as the limitations of their government funded dental benefits. As affordability is most commonly associated with a lack of access to dental care, it is important that providers work with their patients and their benefit providers. This knowledge may help providers better plan and deliver services that allow PLWHA to receive the care that they need and in a way that is affordable for them. However that would also require the health providers to be willing to accept the government benefits, which can be difficult given the low remuneration of these plans compared to current dental office fees. Additional advocacy efforts by patients, HIV-specific organizations, and dental providers to encourage a more equitable reimbursement scheme may also be needed for access to affordable care to be realized.

Secondly, it is important for dental providers to be aware of the types of trauma that PLWHA have encountered over their life, from their diagnosis to societal stigma and discrimination. The experience of trauma had a direct influence on how my participants viewed oral health and their propensity to seek care. Even if cost were not a barrier, the way in which care is arranged and delivered appears important. The education offered to the dental hygiene students and the education for practicing professionals suggested by others indicate that this is necessary for PLWHA to feel comfortable, safe, and respected in a dental setting. Having

knowledge of potential triggers and discussing ways in which to mitigate those will continue to build a trusting relationship between the patient and the provider, and reinforce a person-centered approach to care. Applying the basic principles of TIC can help engage patients who have experienced trauma in their lives and in particular related to oral health care.

Finally, it is important that dental providers are knowledgeable beyond the clinical manifestations of HIV, particular now that PLWHA have a longer lifespan due to the advancement of ART. Education and training should be delivered to future dental professionals with emphasis around the history of HIV and HIV-related stigma. HIV affects the lives of PLWHA in multiple aspects socially, mentally, and physically. The knowledge around this had enhanced better understanding as demonstrated by the dental hygiene students. The acquired knowledge also appeared to have influenced the way services are delivered to the members and created desirable characteristics among the student providers.

Furthermore, my findings show that the members' value and knowledge of the link between oral and overall health seemed to be important in motivating them to attend the clinic and access oral health care as well as follow through with referrals. This finding is consistent with Saurman (2016) who argued that awareness is missing from Penchansky and Thomas' theory. She proposed the intended population needs to have the health literacy and the understanding of the service that is available to them, such as why the service is there, what it does, and how to use it. This is accomplished through effective communication between relevant users, providers, patients, and the community (Saurman, 2016). Further exploration in the awareness dimension may be beneficial to determine how related factors also influence access to oral health care.

The program's lack of available dental services, operation times, and direct contact may be addressed through more active involvement, communication, and coordination with the PLSBC

staff. Peer navigators may be in a position to guide and provide resources for members when the clinic is not operating, especially for members who require immediate dental attention. The program also needs to improve upon finding members an appropriate dental home that meets their personal needs in order to ultimately improve overall access to oral health care for members.

Lastly, an analysis of the oral health data of members could be valuable in determining if the program was effective in improving members' oral health. This could help identify variables that affected members' oral health and evaluate the outcome of the program.

## **5.2 Challenges and limitations**

One of the challenges I encountered was gathering consistent dental chart data as students' records did not always appear calibrated, particularly when the program first began. The students' documentation gradually improved but follow-up with referrals still required more attention in order to better understand why other dental care was or wasn't being accessed.

This study also had some limitations. Given that patient satisfaction forms are completed anonymously, there may be repetition if the same member provided feedback more than once due to ongoing utilization of the program. Therefore the 69 forms completed may not reflect 69 different members who utilized the clinic. If the same member was satisfied/dissatisfied more than once, they may have expressed their appreciation/concerns multiple times.

My findings that describe the health and oral health status of the population at PLSBC cannot be generalized to all PLWHA living in BC or Canada. I did not capture those PLWHA that are hard-to-reach, those who live outside the Greater Vancouver area, or those who did not register with the organization. As the majority of members within the organization identify as the

male gender, the findings should not be assumed to be the same in describing all members, including females.

Another limitation is the generalizability of my findings due to the small convenience sample of members who participated in the personal interviews. However, the themes that I did uncover related to how the clinic influenced different dimension of access and therefore may be transferable to a similar population or organization, but should be further investigated in a larger more representative sample of PLWHA. Moreover, as members who participated in the interviews were recruited through posters placed at PLSBC or through students who informed their patients of my study, there were no members who were past users of the program. I was unable to reach members who discontinued use of the program or those who were not active within the organization to participate in the interviews. Therefore the feedback did not reflect or represent all members who utilized the clinic. This gap may have produced biased responses of those who were satisfied and continued to use the program.

Finally, although I obtained feedback from staff and administrative personnel of PLSBC, I did not gather responses from student providers or the instructor. The students and instructor may have some insight regarding the education proportion of this program and their experience interacting with the members should be followed-up with in the future. However, the focus of this study was to explore members' experience in utilizing the program and the data collected was sufficient to answer my research question.

### **5.3 Conclusion**

The ongoing services and education delivered through this community-based preventive dental program appears to have multiple influences on access to oral health care for members of

PLSBC. Members who continued to utilize the program were predominately male, lived in close proximity, were active and motivated in managing their HIV, oral and overall health, and were generally satisfied with the services offered by the program. The free preventive services enabled members to better utilize their financial resources, making other types of dental services more affordable. Embedding the program within a HIV-specific organization removed the fear of stigma and discrimination and allowed members the opportunity to access the services in a safe manner and setting, alongside other types of services and resources within a convenient location. Members felt empowered to break the societal stigma of HIV through the opportunity to interact and educate future dental professionals about issues that are important in the lives of PLWHA, especially in relation to culturally safe and sensitive dental care. Finally the manner in which the services were delivered, the characteristics of the providers, and the perceived quality of care encouraged members to continue to utilize the program. While many positive influences on access to oral health care were identified, the referral pathway to comprehensive oral care appeared to need improvement.

## Tables

**Table 1. Demographic data**

	<b>n= 170 (%)</b>
Age Groups	
25-34	10 (5.9)
35-44	24 (14.1)
45-54	63 (37.1)
55-64	49 (28.8)
65-74	20 (11.8)
75-84	4 (2.4)
Gender	
Male	146 (85.9)
Female	9 (5.3)
Unspecified	15 (8.9)
Area of Residence	
Downtown Vancouver	122 (72.8)
Downtown Eastside of Vancouver	8 (4.7)
Outside of Vancouver	40 (23.5)

**Table 2. Health conditions and status**

	<b>n=170 (%)</b>
General physician	
Yes	160 (94.1)
No	10 (5.9)
Latest count of CD4+ T Lymphocytes (cells/mm <sup>3</sup> )	
< 200	7 (4.1)
200-499	42 (24.7)
≥ 500	121 (7.1)
Latest dosage of viral burden (copies/mL)	
< 50	164 (96.5)
≥ 50	6 (3.5)
Number of medications	
0	6 (3.5)
1	31 (18.2)
2-3	50 (29.4)
4-5	30 (17.6)
6-7	22 (12.9)
8-9	9 (5.3)
≥10	22 (12.9)

	<b>n=170 (%)</b>
*Types of health conditions	
Hepatitis	42 (24.7)
Respiratory diseases	34 (20.0)
Mental illness	31 (18.2)
Arthritis	23 (13.5)
History of Cancer	21 (12.4)
Gastrointestinal disease	20 (11.8)
Sexually transmitted diseases	19 (11.1)
Kidney dysfunction	18 (10.6)
Hypertension	13 (7.6)
Heart dysfunction	13 (7.6)
History of surgeries	13 (7.6)
Type II Diabetes	7 (4.1)

\*Variable will not add up to total of n.

**Table 3. Dental history and concerns**

	<b>n=170 (%)</b>
Family dentist	
Yes	52 (30.1)
No	118 (69.4)
Dental insurance	
Yes	89 (52.9)
No	81 (47.6)
*Type of dental insurance. <b>n=89</b>	
PWD or PPMB	78 (87.6)
Private	13 (14.6)
Non-Insured Health Benefits	12 (13.5)
Pensioner's dental services plan	3 (3.4)
*Chief dental concern	
Dental assessment	55 (32.4)
Periodontal therapy	52 (30.1)
Pain	23 (13.5)
Loose/fractured teeth	17 (10.0)
Sensitivity	16 (9.4)
Bleeding gums	15 (8.8)
Dry mouth	6 (3.5)

\*Variable will not add up to total of n.

**Table 4. Patient satisfaction survey findings**

	<b>Strongly Agree</b> n=69 (%)	<b>Agree</b> n=69 (%)	<b>Neutral</b> n=69 (%)	<b>Disagree</b> n=69 (%)	<b>Strongly Disagree</b> n=69 (%)	<b>No Response</b> n=69 (%)
Student explained overall dental hygiene care	69 (100.0)	0	0	0	0	0
Student explained time of care	64 (92.8)	3 (4.3)	2 (2.9)	0	0	0
Satisfied with referral	51 (73.9)	0	9 (13.0)	0	1 (1.4)	8 (11.6)
Treated with respect	68 (98.6)	0	0	0	0	1 (1.4)
Care was confidential	69 (100.0)	0	0	0	0	0 (0)
Improved oral health knowledge	68 (98.6)	0	1 (1.4)	0	0	0
Instructor was helpful	68 (98.6)	0	0	0	0	1 (1.4)
Satisfied with equipment and supplies	63 (91.3)	2 (2.9)	3 (4.3)	1 (1.4)	0	0
Comfortable with dental hygiene care	63 (91.3)	2 (2.9)	1 (1.4)	1 (1.4)	0	2 (2.9)
Happy with dental hygiene care	65 (94.2)	0	0	0	0	4 (5.8)
Would return for dental hygiene care	66 (95.7)	0	0	0	0	3 (4.3)

**Table 5. Examples of patient satisfaction survey written feedback**

	<b>Comments</b>
Students	<p>“Always a pleasure to work with students. Excellent care and work”</p> <p>“Very pleased, students were professional ”</p> <p>“Student was professional, clear, thorough. Scaling was gentle and easy.”</p>
Referrals	“Much appreciated the referral to UBC Dentistry for ongoing care”
Equipment and supplies	<p>“Update equipment”</p> <p>“Need a dental chair, not comfortable”</p> <p>“Love the massage chairs”</p> <p>“Suction”</p> <p>“Setup makes neck cramp”</p>
Comfort level	<p>“Was so comfortable, felt completely safe”</p> <p>“More privacy as can hear other patients and students”</p>
Improving oral hygiene	<p>“Floss and brush more on bottom due to crowding and plaque buildup”</p> <p>“Floss regularly, going to see a dentist”</p> <p>“More flossing, brush tongue and molars”</p>
Overall care	<p>“All good. Was treated promptly, did not have to wait, appreciated it”</p> <p>“Saved money for dental. Oral hygiene an asset to have in the clinic”</p> <p>“Efficient, polite, catered to my needs”</p> <p>“Many thanks to oral hygiene, gave good personalized care over the past few years. Happy with program”</p>
Return for care	<p>“Yes”</p> <p>“Yes, because of time, care, information provided.”</p>

**Table 6. Oral health conditions**

	<b>n=165 (%)</b>	<b>Mean (SD)</b>
Teeth present	163 (98.8)	25.1 (5.3)
Missing teeth	158 (95.8)	6.7 (5.2)
1-4	53 (32.1)	
5-8	65 (39.3)	
9-12	20 (12.1)	
13-16	12 (7.3)	
17-31	6 (3.6)	
32	2 (1.2)	
Mobile teeth	56 (33.9)	1.4 (3.1)
Suspected carious lesions	85 (51.5)	1.7 (3.0)
1-4	67 (40.6)	
5-8	13 (7.9)	
≥9	5 (3.0)	
Decayed, missing, and filled teeth	159 (96.4)	13.3 (6.2)
1-4	11 (6.7)	
5-8	19 (11.5)	
9-12	34 (20.6)	
13-16	47 (28.5)	
17-20	24 (14.5)	
21-24	17 (10.3)	
25-32	7 (4.2)	
Abscess or fistula	0 (0)	0 (0)
Oral lesion	12 (7.3)	0.07 (0.3)
Full denture	2 (1.2)	0.01 (0.1)
Partial denture	11 (6.7)	0.05 (0.2)

	<b>n=165 (%)</b>	<b>Mean (SD)</b>
Resin composite		
1-4	119 (72.1) 48 (29.0)	4.4 (4.3)
5-8	39 (23.6)	
9-12	22 (13.3)	
≥13	10 (6.1)	
Amalgam		
1-4	89 (53.9) 51 (30.9)	2.3 (3.0)
5-8	31 (18.8)	
9-12	5 (3.0)	
≥13	2 (1.2)	
Sealant	7 (4.2)	0.07 (0.4)
Temporary restoration	10 (6.0)	0.06 (0.2)
Implant	5 (3.0)	0.05 (0.3)
Dry mouth	21 (12.7)	0.1 (0.3)
*Periodontal health		
Localized gingivitis	3 (1.8)	
Generalized gingivitis	136 (82.4)	
Localized mild periodontitis	33 (20.0)	
Localized moderate periodontitis	34 (20.6)	
Localized severe periodontitis	13 (7.9)	
Generalized moderate periodontitis	6 (3.6)	
Generalized severe periodontitis	3 (1.8)	

\*Variable will not add up to total of n.

**Table 7. Attendance data**

	<b>n=170 (%)</b>
Recare patient	89 (52.3)
Reasons for discontinued care. <b>n=81</b>	
Unable to contact	63 (77.8)
Found a dental home	9 (11.1)
Residence moved out of Vancouver	4 (4.9)
Time conflict with program	3 (3.7)
CD4+ <200 cells/mm <sup>3</sup>	2 (2.5)
Initial dental hygiene care completed	134 (78.8)
Reasons for incomplete dental hygiene care. <b>n=36</b>	
No show	15 (41.7)
Unable to contact	14 (38.9)
Time conflict with program	3 (8.3)
Advanced periodontal therapy needed	2 (5.6)
CD4+ <200 cells/mm <sup>3</sup>	2 (5.6)
Did not show for appointment	
Once	25 (14.7)
Twice	5 (2.9)
Cancelled appointment	
Once	15 (8.8)
Twice	2 (1.2)
Three times	1 (0.6)

**Table 8. Services delivered**

	<b>n=170 (%)</b>
Dental and periodontal assessment	165 (97.1)
Periodontal therapy	134 (78.8)
Fluoride applications	125 (73.5)
Oral hygiene instructions	134 (78.8)
Sealants	1 (0.5)
Temporary restorations	0 (0)
Specific examinations	2 (1)
Sports guard	1 (0.5)
Referrals completed	99 (58.2)
Reasons for referrals. <b>n=99</b>	
Suspected carious lesions and/or defective restorations	54 (54.5)
Fractured teeth	27 (27.3)
Pain	14 (14.1)
Severe periodontal disease	4 (4.0)
Attended referral. <b>n=99</b>	24 (24.2)

**Table 9. Demographic characteristics of members participating in personal interviews**

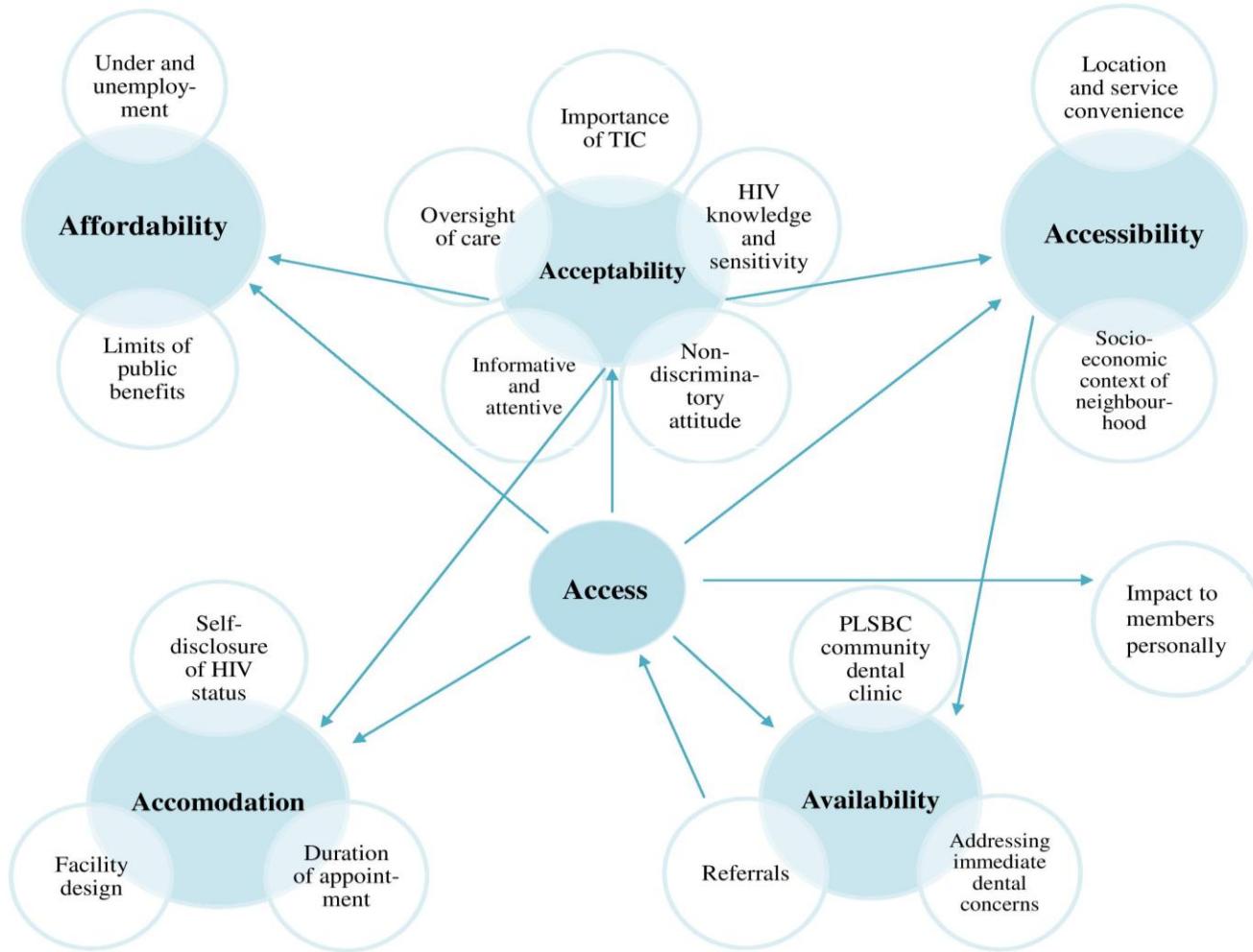
<b>Member</b>	<b>Gender</b>	<b>Age</b>	<b>Area of Residence</b>	<b>Year Diagnosed with HIV</b>	<b>Number of medications</b>	<b>Occupation</b>	<b>Duration using program (years)</b>
1	M	54	DT	2007	1	Retired	3
2	M	65	DT	1991	3	Retired	1
3	M	40	DT	2011	2	Unemployed	2
4	M	65	DT	1989	15-20	Retired	7
5	M	69	Surrey	2007	4	Retired	2
6	M	45	DTES	2001	2	Part time jobs	2
7	M	56	New West	1994	2	PLSBC Staff	1
8	M	53	DT	1993	0	Training manager	2
9	F	48	DT	1995	3	Unemployed	5
10	M	50	DT	1997	1	Part-time jobs	6

DT= Downtown Vancouver, DTES = Downtown Eastside Vancouver

**Table 10. PLSBC staff and administration participating in the focus group**

<b>Position</b>	<b>Staff ID</b>
Administrator	A
	B
	D
	J
	K
	L
Peer navigator	C
	G
	I
Coordinator	E
	F
	H

## Figures



**Figure 1.** Visual map of emerging themes

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## Appendices

### Appendix A : Patient satisfaction survey

Date: \_\_\_\_\_, 20\_\_\_\_\_

Location: \_\_\_\_\_

**How are we doing?** Please tell us how you feel about the care you received by checking the boxes below. The information you give will be kept private.

	Agree	Partly Agree	Neutral	Partly Disagree	Disagree
My student dental hygienist clearly explained the details of my overall care in a way I could understand	<input type="checkbox"/>				
My student dental hygienist clearly explained the time needed to complete my care	<input type="checkbox"/>				
My student dental hygienist was able to provide a referral for additional care that I needed	<input type="checkbox"/>				
My student dental hygienist always treated me with respect	<input type="checkbox"/>				
I feel that my personal information is kept private and confidential	<input type="checkbox"/>				
Attending this clinic improved my oral health knowledge	<input type="checkbox"/>				
The instructors were helpful and respectful to my student dental hygienist	<input type="checkbox"/>				
The student dental hygienist had the equipment and supplies required to provide my care	<input type="checkbox"/>				
I felt comfortable receiving my dental hygiene care at this location	<input type="checkbox"/>				
I am happy with the overall dental hygiene care that I received If no - why ?	<input type="checkbox"/>				
I would come back to this site again for dental hygiene care If no - why ?	<input type="checkbox"/>				

**Some suggestions to improve my dental hygiene care are:**

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**Additional comments:**

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## **Appendix B : Recruitment poster**

### **Title of the study**

Access to oral health care for people living with human immunodeficiency virus attending a community-based preventive program in British Columbia

### **What is the purpose of the study?**

We want to know about your experiences of receiving dental hygiene services at Positive Living Society of British Columbia (PLSBC) in order to modify the services as needed.

### **Who do we want to talk to?**

PLSBC patients who received dental hygiene services here at the society.

### **What will you do?**

Participate in a private and confidential interview that will last about 1 hour.

### **What will we talk about?**

- Your past experience in accessing dental care
- Your experience in receiving dental hygiene services from this program
- How the program can be improved

### **Where and when will the interviews take place?**

Upon your interest to participate in the interview, please contact the co-investigator to set up a date and time. The interview will take place at Positive Living Society. A \$25 gift card will be given to you as a token of appreciation for sharing your experiences.

### **Who can you contact for more information or to participate in the study?**

If you wish to participate in this study, have any questions or require any further information in regard to this study please contact:

### **Co-Investigator**

Iris Feng, Graduate Student, Faculty of Dentistry

University of British Columbia at 604 626 2154

## **Appendix C : Member and staff participant consent**

### **Title of the Study**

Access to oral health care for people living with human immunodeficiency virus attending a community-based preventive program in British Columbia

### **Who is conducting the study?**

Principal Investigator

Dr. Leeann Donnelly, Assistant Professor

Faculty of Dentistry, University of British Columbia

Telephone: (604) 822-5064

Co-Investigator

Iris Feng, Graduate Student

Faculty of Dentistry, University of British Columbia

Telephone: (604) 626-2154

### **Why should you take part in this study?**

You are being invited to take part in this research study because you are a patient (or staff) at the Positive Living Society of British Columbia. The information that you can provide about the dental hygiene services program delivered at Positive Living Society is very valuable and can aid in the sustaining this program and developing future dental programs.

Your participation is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you can decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts.

If you wish to participate, you will be asked to sign this form. If you do decide to take part in this study, you are free to withdraw at any time and without giving any reasons for your decision.

### **What is the purpose of this study?**

A person's oral health has an effect on overall health and well-being, but can be difficult to achieve. People living with HIV/AIDS face unique barriers to accessing a range of health care services. Positive Living Society of British Columbia offers a wide variety of services and

resources to people living with HIV/AIDS. The UBC Dental Hygiene Program has been collaborating with Positive Living Society to offer preventive dental services to members of Positive Living Society to improve oral health and to increase access to dental care. This project aims to determine how the implementation of this preventive dental program influences access to oral health care for its members. The results of this study will contribute to a Master's thesis of the graduate student.

**What will you do if you participate in this study?**

You will participate in a private and confidential tape recorded personal interview (or focus group) that will last about one hour with the co-investigator. We will be asking about your experiences in regards to receiving services from the UBC Dental Hygiene Program.

**What are the potential risks and benefits of this study?**

We do not think there is anything in this study that could harm you or be bad for you. Some of the questions we ask might upset you. Please let the co-investigator know if you have any concerns. Your participation will aid in improving and continuing this program, and developing other oral health programs, which could be benefit to you and other members of Positive Living Society of British Columbia.

**How will your identity be protected?**

Your confidentiality will be respected. Identifying information will be assigned a code number and after it has been processed, any personal information will be removed in order to keep you identity confidential. The list of names and matching code numbers will be stored separately from all other study information. All documents will be kept in a locked filing cabinet in the Faculty of Dentistry at the University of British Columbia. Computer data records will be password protected. You will not be identified by name in any reports of the completed study. Your identity will be kept confidential by the investigators.

**(For the focus group):**

Your identity will be kept confidential by the investigators, however this study involves a group discussion and therefore your identity will be known to the others who are participating. Confidentiality within the group will be the responsibility of the group. We will encourage participants not to discuss the content of the focus group to people outside the group; however, we cannot control what participants do with the information discussed.

**Will you be paid for participating in this study?**

For your participation in the study, you will be given a \$25 gift card for your time.

**(For the focus group):**

For your participation in the study, lunch and light refreshments will be served.

**Who can you contact for more information about the study?**

If you have any questions or concerns about what we are asking you, please contact one of the investigators in this study. The names and telephone numbers are listed at the top of the first page of this form.

**Who can you contact if you have complaints or concerns about the study?**

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca) or call toll free 1-877-822-8598.

**Participant Consent and Signature Page**

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact of your employment or access to further services from Positive Living Society of British Columbia.

Your signature below indicates that you have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study

Please indicate a checkmark in the box to consent for audio recording  
during the interview.

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Participant Signature

Date

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Printed Name of the Participant signing above

## **Appendix D : Personal interview guide**

### **I. Past dental experiences in accessing oral health care**

- A. Can you tell me about your last dental visit outside this program? When was it, where was it, and why did you go?
- B. Do you seek dental care on a regular basis?
- C. Were there any reasons you were not able to receive any type of dental services before? How did this influence you?
- D. Have you had a negative experience with a dental professional before? What was that like, how did you feel, and how did it influence you?
- E. Have you disclosed your HIV status to a dental professional and what was that like?

### **II. Experiences of the program**

- A. Tell me a bit about the care that you received here. Why did you choose to come here? How long have you been coming here?
- B. What was it like to receive services at Positive Living and not a dental office?
- C. What did you like the most about the services that were provided here? What did you like the least?
- D. Have you been referred by the dental hygiene student to another dental clinic before? If yes: Did you follow-up with the referral? If not, why? What can we do to make the referral process better?
- E. Would you seek dental care if it was not offered within PLSBC? How do you feel about the instructor and student providers who already know your HIV status?
- F. Would you follow through with a referral to the PL clinic downstairs? Why or why not?
- G. How do you like the way the room, equipment, and chairs are set up at PLSBC?
- H. Is this location in downtown Vancouver convenient for you?
- I. How do you feel about the services only being available on Wednesdays?
- J. Tell me about your experience booking your appointments and communicating with the clinic when it is not open.
- K. How does the cost of care here influence your decision to utilize services here?
- L. How do you feel about the services provided by students?
- M. What would you like to change in dental private practices to increase more dental access or to make you more comfortable to receive dental care?

### **III. Satisfaction of the program**

- A. What did you like most about this program? What did you like the least?
- B. How has the program met or not met your expectations?
- C. How has this program influence your oral health or your health?
- D. What would improve this program?
- E. Do you have any recommendations for us in modifying this program?
- F. Is there anything that we did not discuss this evening that you think would be important for me to know as we look at revising this program?

## **Appendix E : Focus group guide**

### **I. Experience and impact of the program on-site**

- A. Can you tell me what it has been like having the program running here at PLSBC over the past 7 years
- B. How do you think this program influenced your members? How has it impacted their oral health and overall health?
- C. How do you think it has influenced the organization?
- D. What do you think were some of the strengths of the program? What were some of the weaknesses?
- E. What did you like most about the program? What did you like the least?
- F. How do you think this program is influencing the students and the university?

### **II. Access to dental care**

- A. What do you think of this program in terms of improving access to dental care for your members? How does this program help your members feel or not feel comfortable in receiving preventive dental services at PLSBC?
- B. What do you think of how the dental chairs and equipment are set up at PLSBC?
- C. How do you think the location has affected the members in receiving these services?
- D. How does the service only being available on Wednesdays impact the members receiving the services?
- E. How do you feel about the way appointments are booked with your members and how your members communicate with the students when the clinic is not open?
- F. How do you think the cost of care influence your members' decision to utilize the services at PLSBC?
- G. How do you think your members feel about the services offered by students?

### **III. Satisfaction and Improvements of the program**

- A. How has the program met or not met your expectations?
- B. What would improve this program?
- C. Is there anything that we did not discuss this evening that you think would be important for us to know as we look at revising this program?