Dental care for people living with HIV, a phenomenological approach

Mehrnoosh Alborzi, DDS
Division of Oral Health & Society
Faculty of Dentistry
McGill University, Montreal
October 2017

A thesis submitted to McGill University in partial fulfilment of the requirements of the degree of Master of Science, Dental Sciences.

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ABSTRACT

Background: Oral health care is amongst one of the highest unmet needs of people living with HIV/AIDS (PLHIV); this may be due to barriers they face accessing care, such as stigmatization and fear of discrimination. PLHIV have indeed reported negative experiences at dental offices and with dental staff. However, there is a lack of recent and in-depth studies that capture the current perspectives of PLHIV regarding accessing dental services. In order to respond to the oral health needs of PLHIV, it is thus important to better understand how they access and experience dental care in Canada.

Objectives: Our objective was to better understand the lived experiences of PLHIV with respect to accessing dental care. In particular, we sought to better understand the difficulties and the stigmatization they faced trying to fulfil these needs, and finally to make recommendations for alleviating these difficulties.

Methods: We adopted a participatory approach and an interpretive phenomenological research design. We invited community associations for PLHIV and organizations fighting HIV to collaborate with us at all stages of the research. In order to gain an in-depth understanding of the perspectives and experiences of PLHIV, we used a qualitative approach, namely interpretive phenomenology, which is particularly appropriate for understanding and describing complex and sensitive experiences. We conducted in-depth interviews with eight people living with HIV in Montreal. The interviews were audio-recorded, transcribed verbatim, and interpretively analysed.

Findings: Living with HIV significantly shapes the experiences of people regarding their oral health and accessing dental care. Our participants struggled with an imperfect oral health and a limited access to dental care. Thus they experienced anxiety over managing a fragile oral health for years to come. Although they were generally satisfied with their dentists, they reported isolated negative encounters with the dental staff. Because of these negative experiences, in addition to that of other PLHIV, some participants anticipated being stigmatized in dental settings. To avoid such potential discrimination, they either chose not to disclose their HIV status to the dentists, or to visit a trusted dentist known for accepting PLHIV.

Conclusion: Dental professionals should be aware of and sensitive to the complexities of PLHIV's life experiences and try to accommodate their specific needs. Dentists alongside other members of the society should also tackle HIV stigma in dental settings and society at large.

RÉSUMÉ

Contexte: Les soins de santé bucco-dentaire font partie des besoins non satisfaits les plus importants des personnes vivant avec le VIH / sida (PVVIH); cela peut être dû aux obstacles auxquels ils sont confrontés pour accéder aux soins, tels que la stigmatisation et la peur de la discrimination. Les PVVIH ont en effet signalé des expériences négatives dans les cabinets dentaires et chez le personnel dentaire. Cependant, il y a un manque d'études récentes et approfondies qui saisissent les perspectives actuelles des PVVIH concernant l'accès aux services dentaires. Afin de répondre aux besoins de la santé buccodentaire des PVVIH, il est important de mieux comprendre comment ils ont accès aux soins dentaires au Canada et en font l'expérience.

Objectifs: Notre objectif était de mieux comprendre les expériences vécues des PVVIH en matière d'accès aux soins dentaires. Plus précisément, nous souhaitions mieux comprendre les difficultés et les stigmatisations auxquelles ils étaient confrontés en essayant de répondre à ces besoins, et enfin formuler des recommandations pour atténuer ces difficultés.

Méthodes: Nous avons adopté une approche participative et une conception de recherche phénoménologique interprétative. Nous avons invité des associations communautaires pour les PVVIH et des organisations luttant contre le VIH à collaborer avec nous à toutes les étapes de la recherche. Afin d'acquérir une compréhension approfondie des perspectives et expériences des PVVIH, nous avons utilisé une approche qualitative, à savoir la phénoménologie interprétative, particulièrement adaptée à la compréhension et à la description d'expériences complexes et sensibles. Nous avons mené des entrevues approfondies avec huit personnes vivant avec le VIH à Montréal. Les entrevues ont été enregistrées sur support audio, transcrites textuellement et interprétées de manière interprétative.

Résultats: Vivre avec le VIH façonne de manière significative les expériences des PVVIH concernant leur santé bucco-dentaire et l'accès aux soins dentaires. Nos participants luttaient avec une santé bucco-dentaire imparfaite et un accès limité aux soins dentaires. Ainsi, ils éprouvaient de l'anxiété à gérer une santé bucco-dentaire fragile pour les années à venir. Même s'ils étaient généralement satisfaits de leurs dentistes, ils avaient vécu des rencontres négatives isolées avec le personnel dentaire. En raison de ces expériences négatives ou de celles des autres PVVIH, certains participants s'attendaient à être stigmatisés dans les établissements dentaires. Pour éviter une éventuelle discrimination, ils choisissaient soit de ne pas divulguer leur

statut VIH aux dentistes, soit de rendre visite à un dentiste de confiance connu pour accepter les PVVIH.

Conclusion: Les professionnels des soins dentaires devraient être conscients et sensibles aux complexités des expériences de vie des PVVIH et devraient essayer de répondre à leurs besoins spécifiques. Les dentistes, aux côtés d'autres membres de la société, devraient s'attaquer à la réduction de la stigmatisation liée au VIH dans les établissements dentaires et dans la société en général.

ACKNOWLEDGEMENTS

I would like to begin by expressing my gratitude to my supervisor and mentor Dr Christophe Bedos. From the day I started my studies at McGill everyone told me how lucky I was to have you as a supervisor. They were right, I could not have asked for better! You took me on as your student and guided and supported me every step of the way throughout my master's years. You openly listened to my numerous research ideas and my long monologues and you read my even longer emails and drafts with almost unworldly patience. Your supervising style was inspiring, adaptable, and liberating. I have learned more than I could have ever imagined about being a researcher and a clinician and about myself from you. Your passion for humanity and your call for empathy and social justice in health care have made me rethink the way I look at "care" in health care. Words cannot express my gratitude and how much it all means to me.

I would also like to thank Dr Richard Hovey. Thank you for agreeing to be my co-supervisor and thank you for being so generous with your time and your wisdom, as well as your books (which I will return to you…). Thank you for inviting me to join your reading course and for familiarizing me with the phenomenological way of thinking. Like a true educator, you have forever left a mark in the way I think and approach concepts and conversations with your unique and profound style of thinking and teaching.

I wish to express my most sincere thanks to Liz Lacharpagne and Daniel Lanouette for their insightful guidance and assistance. Daniel, you have been indispensable to realizing this project in so many ways. It was a true honour and pleasure to talk to you and to collaborate with you. Thank you for all your help, and thank you for who you are as a person; I truly believe the world needs more people like you.

I am grateful to all my participants at ACCM for taking the time to share their stories and experiences with me. I would like to give my special thanks to my first participant. Despite your hesitations and concerns, you decided to put your trust in me and your belief in this project. You volunteered to participate because you wished for change and wanted to contribute to your community. I wholeheartedly hope to repay your trust by contributing back to your community.

I would like to acknowledge and thank all members of the Oral Health and Society division, as well as my fellow graduate students for providing me with an almost ideal environment to pursue my studies.

I am sending my biggest thanks to my wonderful friends –you know who you are- for always answering my phone calls, for always being there for me, and for always readily offering me your advice and your friendship, without which this challenging experience would have been impossible to endure at times.

My deepest gratitude goes to my dear parents, who have always been there for me. You have loved me and supported me in countless ways; without you none of this would have been possible. I wish to also acknowledge my dearest brother. You did not do much to be honest, as per usual, but I love you nevertheless!

I would like to acknowledge the financial support I received from the Fondation Marcelle et Jean Coutu, awarded by the division of Oral Health and Society at McGill University.

CONTRIBUTION OF AUTHORS

The candidate, Mehrnoosh Alborzi, wrote all sections of this MSc thesis and performed the literature review. Dr Christophe Bedos and Dr Richard Hovey were the supervisory authors and edited and evaluated the entire work.

The conceptualization of this project was realized through multiple meetings with Dr Christophe Bedos, Liz Lacharpagne, and Daniel Lanouette. The candidate developed the interview guide with the guidance of Dr Christophe Bedos, Liz Lacharpagne, and Daniel Lanouette. The candidate organized the documents for obtaining ethics approval for this study under the supervision of Dr Christophe Bedos. The candidate and Daniel Lanouette recruited all the participants. The candidate conducted all interviews and transcribed them. Dr Christophe Bedos had access to and read all the transcripts. The interpretation of the data was performed by the candidate with the supervision and guidance of Dr Richard Hovey and Dr Christophe Bedos.

1. INTRODUCTION

I was a dental student in my hometown in southern Iran. I was wearing a white coat, with a pair of protective goggles in hand, waiting for my next patient in the maxillofacial surgery ward. The secretary called my name, and handed me a small paper with the name of the patient and the number of one of the dental units written on it. We never really looked at the names of the patients, so my eyes went straight to the unit number: number one! Usually the unit number only told us to which dental unit we should take our patients, but “number one” meant something more; it told us something about the patient. We called it the isolated unit, and it was reserved for patients considered as “high-risk”. Who were these high-risk patients? According to us, patients either with HIV and/or Hepatitis, or those in groups considered to be at a high risk for these pathogens.

When a student’s name was called out followed by the words “unit number one”, our eyes immediately moved towards the patient. Sometimes we asked about the nature of the patient’s condition from our fellow student who was treating the patient, and sometimes we exchanged comments between ourselves: “oh it’s a healthy-looking young girl, what could possibly be wrong with her?” or “he doesn’t really look like someone who has HIV!” Meanwhile, the patient proceeded to unit number one, a unit that was like any other unit to him, not knowing that he was suddenly viewed differently by many of us. Or perhaps he knew… After all, many of the students put on an extra pair of gloves, or a disposable nylon gown over the surgical gown they were wearing over their white coats, and they covered the unit with extra plastic layers. When faced with “unit number one patients”, some dental students including myself, immediately looked at the unit number and the message it implied; we protected the unit by extra layers, and we protected ourselves, before looking at the name of the patient, before asking who this patient was as a person, before thinking what this person wanted and how I could help.

Years later in Canada, I attended a class for the dental students at McGill University where two guest lecturers from HIV/AIDS communities and organizations in Montreal were doing a presentation. I observed the reactions of the students; their questions addressed to the presenters were defensive, and at a few instances the ambiance became quite tense. Only a week later at the same class with the same group of students, but this time with a different group of guest lecturers, I got to make a comparison. The nature of the questions posed by the students changed from “why can’t you see that we as future dentists have the right to protect ourselves” to “what can we, as future dentists, do to better serve your needs”. Almost none of such questions were asked the previous week, almost none of the questions asked in the previous week attempted to understand the experiences and needs of a person living with HIV. I realized that the tendency to separate us as dental professionals from people living with HIV and to prioritize protecting “ourselves” from “them” still prevailed.

After these observations, I came to the realization that dentists and dental students should become more sensitive and empathetic towards their patients that are HIV positive, and that there is a need for humanizing dental care for people living with HIV. For this reason my supervisor and I approached the two people in the HIV communities and organizations who later became our co-researchers: they confirmed that PLHIV still struggled with their oral health and faced difficulties accessing dental care as a consequence of discriminatory or insensitive behaviours from some dental professionals. Perhaps this was partly due to the powerful stigma attached to HIV in society as well as in healthcare settings (1). In fact, a report published in 2012 by the COCQ-SIDA –the Quebec coalition of associations fighting AIDS– showed that 30% of PLHIV who visited dental offices in Quebec reported having negative experiences with dentists, such as the dental professionals being uncomfortable with them or expressing negative attitudes, or even refusing to treat them (2). After doing a preliminary literature review I noticed that the dental professionals’ tendency to focus on themselves –as opposed to PLHIV- in providing dental care was even evident in the literature; the majority of the studies regarding HIV stigma in particular, centred on the attitudes and knowledge levels of dental professionals and students towards PLHIV, as opposed to the experiences of PLHIV with stigma and how it affected their experience of accessing and receiving dental care. Little work has been done to understand this topic and most of what has been done is survey-based studies that lack depth and fail to capture the complexities of the experiences of PLHIV. It is therefore necessary to provide dental care practitioners with PLHIV’s side of the story.

This research was thus conceptualized to achieve the gap in the literature and to address the need for sensitizing dental care practitioners, as suggested by the COCQ-SIDA’s 2012 report (2). By exploring and sharing the experiences of PLHIV with dental care we endeavoured to achieve this. Our objective was to provide a rich detailed understanding of the lived experiences of PLHIV with respect to accessing and receiving quality dental services in Quebec. In particular, we sought to better understand the difficulties they encounter to fulfil their dental needs, including HIV stigma. Finally, we had the objective to provide suggestions for dental care providers, as well as other relevant sectors of the society, in order to improve dental care for PLHIV. We addressed these objectives by taking the following steps:

1. Recruiting PLHIV who have received dental care in Montreal and collecting their experiences through conducting conversational interviews.
2. Discovering the nature of these experiences by identifying major elements of meaning using an interpretive phenomenological approach.
3. Exploring and elaborating upon each element of meaning with the help of the existing literature.

2. LITERATURE REVIEW

HIV Overview

> "*The history of the HIV and AIDS epidemic began in illness, fear, and death as the world faced a new and unknown virus. However, scientific advances, such as the development of antiretroviral drugs, have enabled people with access to treatment to live long and healthy lives with HIV.*" (3)

It is widely believed that HIV originated in Central Africa (4). The first confirmed case of HIV was an African man in the Democratic Republic of Congo (3). It is suggested that the current epidemic started in the second half of the 1970s (3, 4). In 1981, rare and very aggressive conditions usually associated with severely immune compromised patients were reported among healthy gay men in Los Angeles, New York, and California (5, 6). This condition was initially called gay related immune deficiency (GRID) and associated with homosexual behaviours (7), but it soon became apparent that men having sex with men were not the only group at risk. In 1982, the term AIDS (Acquired Human Immunodeficiency Syndrome) was used for the first time (3). Throughout the same year, various case reports from several regions of the world signified that HIV was becoming a global epidemic (3). In 1983, researchers discovered a retrovirus and suggested it was the cause of AIDS (8); it later became known as the Human Immunodeficiency Virus (HIV).

HIV is a retrovirus that causes HIV infection (9). It attacks the immune system of the infected person, in particular the infection-fighting CD4 cells. As more and more CD4 cells are destroyed, the body loses its ability to fight infections and infection-related cancers. If not treated, the infected individual develops three stages of the disease. The acute phase of infection occurs in the first few weeks when the person may experience flu-like symptoms. Then begins a chronic or asymptomatic phase during which HIV multiplies at a low rate. This phase could last for a decade or more and the person may not experience any symptoms. Without treatment, by the end of this phase the number of CD4 cells drop and the individual begins to develop AIDS (9). AIDS is the most severe stage of HIV infection and is diagnosed when the CD4 cell count drops below 200 cells/mm, or when the person develops certain opportunistic infections such as candidiasis of the oesophagus and lower respiratory tract, and Kaposi’s sarcoma (9). If left untreated, the individual with AIDS survives for three years on average (9).

HIV can be transmitted through certain body fluids including blood, semen, and breast milk at all stages of the infection (9). The main ways of transmission are engaging in anal or vaginal sexual activity or sharing syringes and needles for drug injection. Less commonly HIV is transmitted from mother to child and through needle stick injuries (9). The risk of being infected from a single needle stick injury involving an HIV positive person is estimated to be approximately 0.32% (10). This is primarily a risk among healthcare workers but it is minimal, especially if healthcare workers use protective measures to prevent transmission of HIV and other blood-borne pathogens (9). The risk of HIV transmission from a patient to a dental health care worker remains very low, if not infinitesimal. Nevertheless, dental health care workers are at risk of HIV infection; these individuals should thus be aware of it, and follow available national guidelines on occupational exposure to blood borne pathogens (11, 12). In general individuals who are at a higher risk of becoming infected include men who have sex with men, people who inject drugs, prisoners, sex workers and their clients (13).

At the present moment, there is no effective cure for HIV but it can be controlled with antiretroviral (ARV) drugs. These drugs are given in a combination called antiretroviral therapy, or ART (14). The first ARV, called AZT (zidovudine), was approved in 1987 to help patients with AIDS, but it was highly toxic (3, 14). A breakthrough was made in the mid-1990s with the introduction of triple drug therapy, also called highly active antiretroviral therapy (HAART) (14). It was complicated for patients to adhere to the first ART regimens because they were expensive and had severe side effects (14). The current medications are more effective and simple, and they have fewer and less severe side effects than before (15, 16). Some of the most common side effects of these medications include nauseas and diarrhoea, dry mouth, rash, pain, dizziness, difficulty sleeping, and fatigue (15). With these medications what was once a fatal disease, can be a manageable chronic infection (14). Today, with the right medical care and treatments, PLHIV can live almost as long as other people (9, 16). Furthermore, individuals who are on medication and have a low blood viral load are significantly less likely to transmit HIV than those who are not (9).

The Epidemiology of HIV

WHO recognizes HIV as a major global public health issue (13). In 2016, approximately 36.7 million people in the world were living with HIV, 30% of which ignored their condition (17). In the same year, 1 million people died of AIDS-related illnesses while 1.8 million became newly infected (17). It is estimated that since the onset of the epidemic, 35 million lives have been lost due to HIV-related problems (13). Despite that, the number of AIDS-related deaths has dropped by 48% since its highest point in 2005 (17).

In Canada, an estimated 65,040 people were living with HIV by the end of 2014 (18). According to the estimates, only 52,220 of this population were diagnosed with HIV, 39,790 of which were receiving treatment (18). This means that almost 20% of those living with HIV in 2014 remained undiagnosed (18).

HIV transmission is still an issue in Canada and it is estimated that 2,570 new infections occurred in Canada in 2014 (19). HIV incidence is higher among men having sex with men and injection drug users. Men are 3.4 times more likely to become infected than women and incident rates among aboriginal populations are 2.7 times higher compared to those of other ethnicities in Canada. Since new HIV infections continue to occur, while new HIV medications have decreased the HIV-related mortalities, the overall number of PLHIV in Canada will continue to go up (19). Thus the Public Health Agency of Canada predicts an increased demand for HIV-related care and treatment for PLHIV (19).

HIV in Canada is mainly concentrated in certain populations. By the end of 2014, Almost 49.3% of PLHIV in Canada were men who became infected by having sex with men, and those who became infected by injecting rugs accounted for 15.3%. Men whose infection could either be attributed to having sex with men or injection drug use represented 3.2% of the total PLHIV. The status of 31.3% of the total PLHIV was attributed to heterosexual sex. The HIV status of 0.8% all PLHIV could not be attributed to sex or drug use; they were likely infected through other means including blood transfusions, mother-to-child transmission, and needle-stick injuries (19).

The latest regional estimates in Canada are from 2011 (and for statistical reasons should not be compared with the national estimates for 2014). By the end of 2011, 19,300 people were living with HIV in the province of Quebec (20). Men having sex with men accounted for more than half (50.2%) of this population, whereas 29.4% of this population were in the heterosexual category, 15.5% in the injection drug users category, and 4.1% were in men having sex with men and injection drug users exposure categories (20).

Oral Health of PLHIV

Oral Manifestations of HIV

The oral manifestations of HIV are well established in the literature (21-26) and as high as 50% of infected people may suffer from HIV-related oral lesions (27, 28). These oral manifestations are among the earliest indicators of HIV infection and are associated with lower CD4 cell counts and the progression of the infection into AIDS (24-26). The most common oral lesions are opportunistic infections including oral candidiasis and oral hairy leukoplakia, Kaposi's sarcoma, necrotizing ulcerative gingivitis and necrotizing ulcerative periodontitis (24-27). Other common lesions include ulcers, diseases of the salivary glands, HPV (papillomavirus) and HSV (herpes simplex virus) (25, 26). Periodontal diseases are also more common and severe, and progress more rapidly among PLHIV (21, 22, 27). HIV-related periodontal diseases can be responsible for severe acute oral pain, ulcerations, bone loss and halitosis (22, 25, 26).

PLHIV who do not receive ART are prone to these common manifestations of HIV (25, 26). Although ART can decrease the prevalence of such lesions by 30% (25, 26), PLHIV still have significant oral health needs, particularly in relation to their periodontal health (29). Additionally, many ART agents could potentially have adverse orofacial effects such as ulcers, facial lipoatrophy, and xerostomia (23, 26). The latter, which can significantly increase the risk for caries and gingivitis (26), has been reported to remain an issue for as much as 66% of PLHIV after receiving ART (29).

The Impact of Oral Health on the Lives of PLHIV

Oral lesions associated with HIV can seriously impact on the lives of people: they could be debilitating (21, 29) and even possibly life threatening in the case of periodontal diseases. The latter are associated with diabetes mellitus (30) and cardiovascular diseases (31), which are responsible for the increased non-AIDS related deaths in PLHIV (32). Oral diseases can cause discomfort and pain, and can make chewing, talking, smiling and socializing difficult (21, 29). PLHIV are at a disadvantage regarding the social impact of their oral health (29), which is also strongly associated with mental and physical health (25). In brief, oral lesions can significantly impact the quality of life for PLHIV and this impact is higher among PLHIV compared to the general population (21, 33).

PLHIV who had not visited a dentist in more than a year have reported a lower oral health related quality of life (33). Access to regular dental visits and oral treatments as well as good oral hygiene are important for PLHIV and can improve their oral health and oral health related quality of life (29, 33). Therefore, the management of HIV infections should include oral health care (26) and dentists can play an essential part in this process; not only in diagnosis and staging HIV infections, but also in managing the health and quality of life for PLHIV (25, 26). As oral health issues are more prevalent and more severe for PLHIV, they have a significantly higher need for oral healthcare.

Unmet Dental Needs of PLHIV

Despite the significance of oral health for PLHIV, their dental needs are not met according to several studies conducted mostly in the US (34-38). A high percentage of PLHIV, more than half in some studies, indeed reported having unmet dental needs (34, 37, 39), which is substantially higher than in the rest of the population (39). It needs to be noted that their unmet dental needs are almost as twice prevalent as their unmet medical needs (38). It is no wonder then that a significant proportion of PLHIV evaluate their oral health as fair or poor while evaluating their general health as good (35, 37).

Significant disparities exist within PLHIV regarding their oral health, perceived unmet needs, and utilization of dental care (37, 40, 41). Unmet dental needs are particularly associated with social and economic factors (39). Women, non-white citizen in the US, people with drug addiction, lower income levels and no dental insurance are more likely to have unmet dental needs (34, 37-39, 42). HIV-related health factors such as immune competence, the number of years since HIV diagnosis, and the stage of HIV infection are also associated with unmet dental needs of PLHIV (34, 37, 43).

Dental Care for PLHIV

Use of Dental Services among PLHIV

According to quantitative studies, PLHIV who have dental insurance, higher education and income levels are more likely to seek dental care than those who are less privileged (40, 41, 43). Fear of dentists and perception of fair or poor oral health are also associated with failure to use dental care (37, 42). Besides, PLHIV with higher use of medical and psychological care are more likely to use dental services (40, 41).

According to a qualitative study conducted in the US, concerns for appearance, and consequently self-esteem and social relationships, are motivating factors for PLHIV to seek dental care (44). Childhood dental experiences and beliefs about the importance of oral health for PLHIV also influence dental health seeking behaviours: those whose caregivers emphasised on the importance of dental care were more likely to visit the dentist on a more regular basis (44). In comparison, those who reported limited experience of dental care in their childhood, partly because of poverty, were more likely to have a problem-focused care seeking behaviour (44). Therefore, even when financial barriers are lifted for those from disadvantaged backgrounds, seeking preventative care may be difficult for them because they were not socialized to do so (45).

PLHIV tend to visit dentists less frequently after being diagnosed with HIV (45) and delay seeking care (46), or they stop visiting dentists altogether (47). In one of the largest studies to examine oral health care for PLHIV in the US, more than half of the 2,469 participants reported not having visited a dentist in the previous two years (48). In another study, also in the US, 43% of the participants had not visited a dentist in over one year (42). Overall, despite having a greater need for accessing dental care compared to the rest of the population (48), PLHIV are receiving less dental care than they need (42): as high as 78% of PLHIV have reported failing to get dental care when needing it (34, 35, 42). Although PLHIV need regular visits they encountered problems accessing dental care everywhere, including in the industrialized countries (36).

Barriers to Accessing Dental Care for PLHIV

Failing to obtain dental care is partly because PLHIV face various barriers to accessing dental care and finding a dentist (42, 49). The main and most commonly cited barrier according to quantitative studies is the costs and inability to pay for dental treatments, partly due to lack of dental insurance (34, 35, 37, 41). HIV positive participants of a survey study in Canada were more likely to have received dental care in the previous year if they had a dental insurance or could otherwise afford it (50). Not having a usual source of dental care is another reported barrier to using dental services (48). Other barriers include dental fear, low motivation, and failing to make an appointment (34, 37, 42). Another barrier to accessing dental care may be the more pressing mental and physical problems that interfere with the use of dental services, as individuals with poor mental and physical health are less likely to use dental care (43).

A qualitative study of barriers and facilitators of accessing dental care (45) provided more comprehensive information and identified seven barriers: dental anxiety and fear of pain and needles, administrative procedures including paperwork needed for referrals, long waiting times, problem focused care-seeking behaviour (as opposed to regular visits), transportation issues, psychological issues and dentists' reluctance to treat PLHIV (45). On the other hand, having dental coverage and an assigned case manager or social worker were identified as facilitators of accessing care. In addition, PLHIV were more likely to engage in care if their dentists were accepting and respectful towards them. However, some found it difficult to locate a dentist who would take their insurance or willing to treat HIV positive patients (45). Another qualitative study added that concerns over confidentiality might stop PLHIV from accessing dental care (51).

In another qualitative study, researchers used the photographs that the 12 participants took over the course of two weeks to identify themes associated with accessing dental care (52). The emerging themes included HIV medication, transportation, healthcare staff, and various social circles that could act as both stressors and support in accessing care. The researchers combined these themes to present three meta-themes as indicators of stressors and support in accessing dental care. One meta-theme was PLHIV's pride about the feelings of ownership about their lives and their health, indicating that they take pride in managing their health. The second meta-theme was maintenance of mental health and the PLHIV's struggle to cope with mental illness, especially considering their complex and even traumatic histories. The last meta-theme was stigma and the role it played in the lives of PLHIV. The researchers suggested that health providers might not fully appreciate the constant struggle of PLHIV with stigma, which posed a social barrier to accessing care. Although this study was holistic, taking the histories and lives and general struggles of PLHIV into account, the researchers lost the focus on dental care and failed to explore complex themes such as HIV stigma in more depth (52).

Both qualitative and quantitative literature from the early or current days of the epidemic, suggest that stigma and discrimination against PLHIV by dental professionals act as a potential barrier to accessing dental care (45, 47, 49, 52, 53). Discrimination can influence PLHIV's access to dental care as well as the perceived quality of care (49). PLHIV may have concerns about HIV-related refusal and discrimination in dental settings (41) and consequently may be reluctant to disclose their HIV status to their dentists (42, 46, 53, 54). Research in Canada reveals that between 13 to 25 per cent of PLHIV do not disclose their HIV status to their dentists, mainly due to fear of discrimination and refusal, or out of concern for their confidentiality (2, 54, 55).

Overview of HIV Stigma

HIV Stigma in the Society

HIV stigma refers to prejudice, stereotyping, and the negative behaviours and abuse directed at PLHIV (1). From the beginning of the epidemic, HIV/AIDS has been a strongly stigmatizing illness. It has not simply been medicalized as a disease, but also moralized as a stigma. Various traits of the disease have the potential to trigger stigma, as HIV uniquely combines concepts of sex and drug use with contagion and death (1). An individual who is stigmatized because of HIV could be perceived as someone deviant from normality, and therefore threatening to the society. This deviance could be contagiousness as well as immoral deviation from moral standards such as promiscuity and perversion. On top of that, HIV infection has always been more prevalent in already marginalized and stigmatized populations such as gay men, drug users, and in Canada the aboriginal populations (1, 19). Stigma can manifests itself in actions including abusing, exposing, and rejecting the HIV positive individual that can be very subtle or extreme (1).

HIV stigma remains prevalent around the globe. According to UNAIDS, in 35% of the countries with available data, more than half of the population has discriminatory attitudes towards PLHIV (56). Stigma and discrimination against PLHIV still prevail in Canada as well. A national survey conducted in 2012 revealed that although the majority of Canadians had little tendency to stigmatize PLHIV, 22% exhibited a moderate degree and 7% held a high degree of stigma against PLHIV (57). This survey also indicated that 19% and 15% of Canadians showed moderate and high levels of discrimination against PLHIV respectively, not believing that the rights of PLHIV should be protected or believing that PLHIV's rights should be limited (57).

The same survey also revealed that the population of Quebec was the most likely to feel anger (10%) and fear (23%) towards PLHIV (57). Despite this, people in Quebec have an overall positive attitude towards PLHIV (58). However, it is concerning that their attitude have showed only a slight improvement throughout the years (58). High levels of homophobia and low knowledge of HIV transmission have been reported as the most significant predictors of stigmatizing attitude towards PLHIV in Quebec (58, 59). Male Quebecers over 50 years of age with less than 14 years of education were the most likely to stigmatize HIV (58).

Stigma and discrimination can have a detrimental impact on the quality of life of the stigmatized individual. It may lead to social isolation, lower social achievements, and low self-esteem, thus impeding the mental and physical health and overall wellbeing of the person (1). HIV stigma has been associated with avoiding HIV testing, lower HIV medication adherence, delay in accessing care and reluctance to disclose HIV status to healthcare providers (1). It can also indirectly interfere with the PLHIV's health management by decreasing social support and contributing to mental health issues (1).

HIV Stigma in Healthcare Settings

Literature on HIV stigma in healthcare settings is extensive. Therefore, in this section, I will mostly refer to a book chapter on HIV stigma (60) in addition to a review of qualitative evidence realized by Chambers et al. (61); I will also refer to several qualitative studies conducted in Canada (62) and Quebec (63, 64), as our research is a qualitative study of healthcare-related HIV stigma in Montreal. It is important to note that HIV stigma and its manifestations change through time (1). I chose these studies because they were conducted in the last decade so they are more likely to present a realistic picture of the current HIV stigma in healthcare settings.

Experiences of HIV stigma enactment in healthcare settings have been reported from the beginning of the epidemic and continue today in both low-income and high-income countries (61). In the early years of the epidemic, in the 1980s and early 1990s, HIV stigma was widespread among a considerable fraction of health care providers and trainees. Much has changed with the advances in HIV treatment that altered the face of HIV as a deadly disease and with the fact that HIV is no longer limited to certain stigmatized minorities (1). But to what extent these changes have modified the attitudes of healthcare provider towards PLHIV is still uncertain (60). Studies reveal that a significant minority of PLHIV are still subjected to stigmatization in healthcare settings. Although PLHIV are experiencing less instances where HIV stigma directly influences their health care, such as delaying or refusal of treatment or inadequate care provision, they still report negativity on behalf of the healthcare professionals that adversely influences their care (60).

Examples of negative behaviours from healthcare providers towards PLHIV include avoiding physical touch and eye contact, being judgemental and blaming, having a humiliating behaviour, showing discomfort, and not maintaining confidentiality of the patient (60, 62, 63, 65, 66). PLHIV may also feel moralized, infantilized, and neglected by healthcare providers (61). They may as well experience overlapping stigma in healthcare settings due to racialization and judgment on their sexual orientation or socioeconomic status (61-63). In addition, the nervousness of clinicians and the use of excessive precautions (double gloving, placing protecting covering or clothing), as well as breach of confidentiality in order to inform and protect other colleagues, are perceived by PLHIV as indicators of exaggerated fear of HIV transmission (61, 65).

According to a qualitative study conducted in Quebec (64), instances of HIV stigmatization in healthcare settings are episodic and isolated. Nevertheless, the participants of this research described many situations where they believed that they were discriminated against by healthcare providers (64). The examples of such behaviours were ranging from staring and judgemental looks, or gossiping and asking inappropriate questions to showing signs of discomfort, keeping distance and avoiding contact. Some even reported that healthcare providers delayed or refused care provision entirely. Additionally, some felt negatively about the fact that

PLHIV are expected and requested to disclose their status in healthcare settings and that healthcare providers use precautions specifically targeted at them (64). The researchers classified these normalized risk management strategies in healthcare settings as a structural and systematic stigmatization (64). As a consequence of HIV stigma, the participants sometimes avoided environments they believed to be stigma-intensive, such as emergency rooms (64). They preferred to stay within HIV healthcare networks, where they felt comfortable and safe, as the idea of receiving care outside the network made them feel uncomfortable and vulnerable (64).

HIV discrimination in healthcare settings reflects the existing misconceptions and stigmatizations against PLHIV in the society (61). In this way healthcare settings become another environment where stigmatization is manifested at an institutional level by the system to whom PLHIV are supposed to entrust their health (61). It is important to note that stigma in healthcare settings can be particularly damaging for the health of PLHIV as it is associated with poor access to care, lower treatment adherence, and less appointment attendance (60, 61). Because of HIV stigma disclosing HIV status becomes a dilemma for PLHIV (62). On one hand non-disclosure is a solution to alleviate stigma, on the other hand some viewed non-disclosure as a "creator of stigma surrounding the illness" (62). Finally, patients may avoid seeking care altogether out of fear for their confidentiality in their communities or being stigmatized in healthcare settings (60, 61).

HIV stigma and other overlapping stigmas in healthcare settings should be addressed to alleviate such problems and for PLHIV to receive care that is attentive, empathetic, and respectful of their complex experiences (63). It is important to create a supportive environment free from judgement to facilitate access to care and to promote health seeking behaviours and treatment adherence (61).

HIV Stigma and Dentistry

A consistent body of literature gives evidence of stigmatizing and discriminatory behaviours of dental healthcare practitioners against PLHIV, which adversely affect PLHIV's access to dental care and the quality of received care (49). Mainly two types of studies have been conducted to document HIV stigma in dental settings: studies surveying PLHIV about the behaviours of the dental professionals (2, 49, 50, 55) and studies in which researchers pretending to be HIV positive call dental offices to investigate if they would be treated any differently (2, 67-69). These studies reveal that a significant number of PLHIV are refused, referred, or treated differently in dental clinics (the percentage of those who report negative behaviour range greatly from one study to another). In the mid-1990s, McCarthy et al. provided evidence of HIV stigma at dental offices in Canada by showing that 15% of respondents had been refused because of HIV (50, 55). According to a study in the US, PLHIV who had a public benefit for poor people (similar to welfare) were twice as likely to be refused as PLHIV with private insurance (68).

In 2012, the COCQ-SIDA (Coalition des Organismes Communautaires Québécois de Lutte Contre le SIDA) conducted a study on discriminatory behaviours against PLHIV in Quebec dental clinics (2). They showed that after disclosing their HIV status to their dentists, 70% of the respondents had an overall good clinical experience. The other 30% however, reported that either the dentist or the dental hygienist manifested signs of discomfort or a changed attitude. Four per cent of these respondents were refused and 13% had been asked to come as the last appointment of the day because they had HIV, and a few even reported paying extra fees for sterilization of the equipment (2). In addition, the researchers contacted 769 dental offices in various regions of Quebec to find out if it was possible to book an appointment as a person living with HIV without being treated differently. This was not the case in 14% of the calls. In almost half of these cases, the researchers were told that the appointment needed to be at the end of the day, mainly for sterilization and additional precautions. In 30% of these cases, the dental offices refused to give the callers an appointment, either by referring them to another dentist, or by claiming that the dentist did not have the necessary equipment or knowledge to treat them. Many callers were notified that their appointments would take longer, and the most common justification was the need for extra precautions and increased sterilization (2).

Despite the issue of existing stigma in dental settings and its considerable role as a barrier to accessing the much-needed dental care for PLHIV, little work has been done to understand HIV stigma in dentistry from the perspective of PLHIV. Surprisingly, a quick review of the literature in the post antiretroviral therapy era shows that the majority of the research done on HIV stigma in dental settings focuses on the attitudes and the knowledge levels of dentists and dental students, and sporadically of dental educators and dental staff such as dental hygienists and assistants. This may be due to the fact that dental practitioners and students are far more accessible as research subjects than PLHIV. Furthermore, the majority of these studies have been conducted in Asian, African, and Middle Eastern countries, and thus their findings may not be applicable to the Canadian context. We need to add that almost all of these studies are questionnaire-based surveys that fail to provide the deep understanding that a complex social phenomenon like HIV stigma deserves.

That being said, such studies provide further evidence that some dental practitioners have negative attitudes towards PLHIV (36). Although there appears to be a trend towards greater acceptance, problems still persist and dentists as well as dental students report being hesitant to treat HIV positive patients (36). A survey of licensed dentists in Canada in 1999 (70) revealed that one in every six dentists reported having refused HIV positive patients. Respondents also expressed unwillingness to treat PLHIV or those who are in high-risk groups for HIV, especially injection drug users (70). These dentists were mainly concerned about losing other patients, or difficulties of managing their staff and their fears, personal risks of treating PLHIV, and financial burden of using more infection control precautions (70). Low belief in ethical responsibility, fear of cross-infection, the perceived norm of colleagues, low optimism, and low comfort with homosexuality were best predictors of refusing care to PLHIV (36, 70).

Although this type of research could be helpful in evaluating and understanding the reasons behind the reluctance of some dentists to treat PLHIV, it fails to explore the perceptions and experiences of those who are subjected to discrimination and struggle with difficulties accessing care. There seems to be a gap in the literature regarding dental care from the perspectives of PLHIV. At the time of writing the proposal for this project, we only identified one such article that aimed to study HIV stigma in dental settings. IN 2015 Patel et al. published a qualitative study (71) in which they asked PLHIV about anticipating stigmatizing behaviour, changing dentist after diagnosis, disclosing HIV status, and hesitancy to visit dentists. The study was successful in demonstrating that PLHIV face both HIV related concerns as well as pragmatic difficulties accessing dental care (71). However, its findings add little to the existing quantitative literature, neither delving deep into nor expanding on the complexities of the experiences of PLHIV, including HIV stigma. Perhaps this is partly due to its methodological weaknesses and its overly quantitative approach in adapting a qualitative methodology, for example by interviewing 66 participants and reporting their findings in percentages.

While we were in the process of obtaining ethics approval for our project, Brondani et al. published a study around HIV stigma in dental settings in Vancouver, Canada (72). The researchers took a descriptive qualitative approach to offer a comprehensive summary of the experiences of PLHIV with stigma. Their study described the fear and anxiety of their participants related to the reactions of dental professionals and their experiences of stigmatizing behaviours. Although according to their participants the attitudes of dental professionals have been improving in the recent years, the researchers concluded that HIV stigma could prevent PLHIV from receiving optimum care and might damage their overall wellbeing (72). This study achieved its objective of providing a detailed description of HIV stigma in dentistry and its findings can be applied to the current reality of the Canadian context. Having said that, the study focused on one barrier of accessing dental care for PLHIV, which was stigma (72). We will try to have a more comprehensive look at several aspects of dental health care for PLHIV, including how they experience oral health. We also aim to explore HIV stigma in dental settings in more depth. Furthermore, Brondani et al. use a descriptive qualitative approach as opposed to our phenomenological method of enquiry that is more suitable for exploring a deep understanding of complex life experiences of PLHIV.

Conclusion

In conclusion, we still know very little about how PLHIV access and experience dental care. Many studies on this subject were conducted in the 1980s and 1990s and may not apply to our current Canadian context. In addition, the majority of the studies about PLHIV and dental care are based on quantitative surveys and thus fail to provide an in-depth understanding of this sensitive and complex phenomenon. The few qualitative studies on the matter are focused on very specific aspects of dental care, such as PLHIV's satisfaction with certain care models (73, 74) or barriers to accessing dental care (45, 52). In addition, some have serious methodological weaknesses with little description of the methodology (45, 51). Furthermore, when it comes to stigma, most studies focus on health care providers and do not capture the perspectives of PLHIV.

In order to increase PLHIV's oral health and respond to their needs, it is thus important to better understand how they access and experience dental care in Canada and this is what our study aims to achieve. To our knowledge, this is the first phenomenological enquiry of the experiences of PLHIV accessing dental care.

3. METHODOLOGY AND METHODS

The aim of this study was to construct a sensitive and deep understanding of what it means for PLHIV to access and receive dental care. In particular, I wished to understand the difficulties and barriers PLHIV face accessing care and the role of HIV stigmatization in this regard. My ultimate purpose was to sensitize dentists and dental students to the needs of PLHIV, develop action guidelines and educational tools to help improve how PLHIV receive and perceive dental care, and to eventually eliminate the dental health disparities faced by PLHIV. Therefore, to best address these aims we adopted a methodological framework with a participatory and qualitative approach, and an interpretive phenomenological research design.

Participatory Approach

Communities have expressed dissatisfaction to researchers who parachute in their communities from the outside and inquire about sensitive issues, and then leave without providing solutions or information (75). Moreover, conducting research in a community without knowing the people and the context makes the social validity and social relevance of the research project questionable (76). Increasingly, health researchers are encouraged to engage communities in the course of the research (76, 77). Participatory research is an umbrella term for research approaches that recognize the importance of including those who are intended to benefit from the research in the various stages of research process (77). Participatory research is defined as "systematic inquiry, with the collaboration of those affected by the issue being studied, for the purpose of education and action or affecting change" (78). It focuses on forming partnerships between academics and non-academics such as community members, activists, and decision makers in order to develop and implement effective strategies for change and to empower the underserved communities (75). Participatory research has great potential for translating knowledge into action and addressing social justice. Participatory research driven by values of social justice gives primacy to the needs and interest of vulnerable subgroups, by including those victimised by social injustice as well as activists and community organizers (77). Choosing a participatory approach provided us with a chance to collaborate with people who are directly affected by HIV/AIDS and HIV right activists who develop and evaluate community actions supporting and improving the quality of life of PLHIV. We also believe that this approach can pave the way for mutual trust and understanding between PLHIV and dental health practitioners.

Our Co-Researchers

This research is based on the partnership between three sectors: Dental educators, HIV/AIDS rights activist, and community organizations for PLHIV:

1. Dental educators: The dental educators in this participatory research project are Christophe Bedos, PhD, and Richard Hovey, PhD, who are members of my supervisory committee. Dr Bedos and Dr Hovey are associate professors in the Division of Oral Health and Society with the Faculty of Dentistry at McGill University.
2. HIV/AIDS rights activist: Liz Lacharpagne is a lawyer and coordinator of human rights and HIV/AIDS program at COCQ-SIDA (Coalition des Organismes Communautaires Québécois de lutte contre le SIDA). COCQ-SIDA is a group of community organizations working on issues affecting people living with HIV and all populations at risk of being infected with HIV in Quebec. The mission of COCQ-SIDA is to bring together Quebec community organizations involved in the fight against HIV / AIDS and to provide leadership in order to stimulate, support, consolidate and promote independent community action in the fight against HIV / AIDS (79).
3. Community organization and community member: Based on the participatory research principle of partnership with community members, we collaborated with Daniel Lanouette, who is a coordinator of group services at ACCM (AIDS Community Care Montreal). ACCM is the only English speaking community organization in Quebec that provides support to people living with HIV/AIDS, as well as hepatitis C. ACCM envisions a society free from HIV/AIDS stigma so that every person living with HIV/AIDS can get the support they need. As a part of its mission, ACCM promotes active partnership with other organizations to overcome stigma and discrimination (80).

Networking with community members and organizations could be a challenging and lengthy process. However, I was fortunate enough to be introduced to our co-researchers at ACCM and COCQ-SIDA through my supervisor Dr Bedos, who had previously collaborated with them.

Doctor Bedos asked me to join his class for third year dental students to meet Liz Lacharpagne and Daniel Lanouette who were guest presenters. In addition to the importance of this presentation for its potential role for knowledge translation through educating and sensitizing dental students, it was particularly interesting for me because it provided me with the opportunity to observe the reactions of dental students to this issue and reflect. (It was after the first presentation that I realized the importance of doing this research).

After conducting a preliminary literature review to see what research had been done on the issue of access to dental care for PLHIV, I developed a brief research outline. This outline was then sent to our co-researchers in the community to assess whether the community felt that there was a need for research on the issue. After receiving positive feedback, my supervisor and I organized an initial meeting with Liz Lacharpagne and Daniel Lanouette to invite them to collaborate with us in all stages of the research project. Issues discussed in this meeting included defining the research objectives to address the needs of the community and refining the research question, designing the interview guide, the inclusion and exclusion criteria of the participants, recruitment strategies, and possible avenues of knowledge translation. These issues were further discussed through emails. Due to the sensitive nature of HIV/AIDS, the contribution of our co-researchers in the community was particularly necessary in designing the interview guide to ensure that all the questions are appropriately phrased and within the scope of our study. Additionally I had several individual phone calls and meetings with Daniel who played a crucial role in introducing me into the community, identifying and recruiting participants, developing strategies, and guiding me overall.

Qualitative Approach

Methodological Framework and Worldview

For our study design we chose a qualitative approach, namely interpretive phenomenology. Qualitative research is pertinent when an issue needs to be explored (81). We conduct qualitative research when we want to gain an elaborate and in depth understanding of an issue. Qualitative research is conducted in a natural setting, meaning that instead of bringing individuals to a lab or sending out questionnaires, the researchers collects data on site and by talking directly to people in their own contexts. Therefore, qualitative research is suitable for understanding the context in which an experience occurs. We also use qualitative research when we wish to study a phenomenon that is difficult to capture by quantitative measurements, such as complex human interactions. Through qualitative research we can hear the voices of people who participate, an offer an opportunity to tell their stories by minimizing the power relationship that often exists between researchers and their subjects (81).

Qualitative research is generally associated with constructivist or transformative worldviews. Worldview, also called paradigm, has been defined by Creswell as "general philosophical orientations about the world and the nature of research that a researcher brings to a study" (82). Constructivists believe that reality is a construct of human intelligence and therefore subjective. Individuals seek meaning in their experiences and these meanings are varied and complex. Consequently this worldview leads the researcher to explore this complexity of meanings instead of narrowing it down into a few categories, by posing open-ended questions and listening carefully to what participants do and say. Another group of researchers with a more transformative worldview focuses on the needs of the marginalized groups of people and issues of social justice and discrimination. They believe that research should include an action agenda for helping marginalized people and minorities (82). We acknowledge that PLHIV are underserved when it comes to their oral health needs and that their experiences regarding oral health care is complex and needs to be explored in more depth and detail. These beliefs align well with the constructivist and transformative worldviews that demand a qualitative approach to tackling problems and issues.

Phenomenology: Research Approach and Philosophy

Phenomenology as a Philosophy

"[Phenomena] have something to say to us - this is common knowledge among poets and painters. Therefore, poets and painters are born phenomenologists. Or rather, we are all born phenomenologists; the poets and painters among us, however, understand very well their task of sharing, by means of word and image, their insights with others - an artfulness that is also laboriously practised by the professional phenomenologist. (83)*"*

We have selected a phenomenological approach for our study because I sought to construct a sensitive and meaningful understanding of the experiences of PLHIV with oral health care and phenomenology is particularly appropriate for understanding complex and sensitive experiences (81). Phenomenology is popular in social and health sciences and can bring valuable insight into issues that are directly dealt within the medical fields (82, 84). The purpose of phenomenology is to identify the universal essence of a particular phenomenon by understanding how the participants make sense of experiencing that phenomenon (81). In our research, we wish intended to understand how dental care is experienced by people living with HIV and phenomenology as a research approach is most useful when trying to understand an experience as it is understood by those who are living with it (85).

Phenomenology is not just a qualitative methodology, it is also a philosophy heavily inspired by the writings of the German mathematician, Edmund Husserl, as well as Heidegger, Sartre, and Merleau-Ponty who expanded on Husserl's views. The philosophical perspective of phenomenology can be a rewarding approach for examining theoretical and practical issues in the domain of healthcare and clinical practice and healthcare ethics. Therefore, no phenomenological work is complete without understanding the strong philosophical underpinnings of the approach (81, 84, 86).

The Phenomenon in its ordinary sense is what shows itself directly; phenomenon in a phenomenological sense is "that which already shows itself in the appearance as prior to 'phenomenon' as ordinarily understood and as accompanying it in every case, can, even though it thus shows itself unthematically, be brought thematically to show itself; and what thus shows itself in itself… will be the 'phenomena' of phenomenology". Accordingly, the conception of phenomenology is "to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (87). There are as many different conceptions of phenomenology as there are phenomenologists, however all phenomenological approaches are based on the motto of the fountainhead of modern phenomenology, Edmund Husserl, "to the things themselves (*Zu den Sachen*)" (84). The philosophy of phenomenology described by Husserl and Heidegger Phenomenology endorses matters of epistemology (how we know) as well as ontology (what is). However, there are some differences between the viewpoints of Husserl and Heidegger, resulting in two distinct schools of thought within phenomenology (88).

Eidetic or descriptive phenomenology is largely based on the work of Husserl, the founder and figurehead of phenomenological movement. Although many philosophers have practiced phenomenology throughout centuries, phenomenology as we know it came to full bloom with Husserl in the first half of the 20th century. In the face of the ideological crisis after the First World War Husserl strived for developing a method that could grant absolute certainty to the disintegrating society. He sought to secure absolute insight into the essence of phenomena to yield a concrete descriptive insight. Husserl argued that any information about objects in the outside world is unreliable since he refused the belief that objects exist independently. Hence people can only be certain about the way things present themselves to their consciousness (88, 89). Therefore for Husserl the purpose of phenomenology is to rigorously study things as they appear without any bias, in order to attain a fundamental understanding of human consciousness and experience (86). The focus of Husserl's phenomenology is on immediate consciousness and requires that descriptions of the experience be obtained before the person had reflected on their experience (pre-ontological). To reach this objective Husserl introduces the concept of "epoche" or bracketing, in which the phenomenologist suspends all judgements and pre-existing experiences to instead take a fresh analytical perspective toward experience (81, 90). In order to do so, the investigator should first make these preconceptions overt and as clear as possible. By refusing the belief of an existing reality in the outside world, Husserl's phenomenology stands in contrast with Cartesian notion of the dualism of mind and body that is the rationale behind modern natural sciences. However, it somehow aligns with the positivist paradigm in its attempts to maintain objectivity by means of presenting a pure description without resorting to interpretation (86).

Heidegger on the other hand, disagrees with Husserl on the importance of description and advocates for a hermeneutic method that views lived experience as an interpretive process (87). The major difference between the two philosophers is their stance on bracketing. According to Heidegger it is impossible to step outside of one's pre-understandings as the Husserlian notion of bracketing requires, simply because they already exist. Thus, instead of avoiding these pre-understandings the investigators should be aware of them and how they may influence their interpretations (91, 92). Additionally, as opposed to Husserl who was more focused on epistemological questions (how we know) and developing new philosophy that attended strongly to its own methodology, Heidegger was more focused on ontological questions (what is) (87, 88). Heidegger’s main concern was to raise the question of being- how we make sense of things (87), or to be more precise what it means to be (85). Hermeneutic inquiry grounded by Heidegger is referred to simply as hermeneutics or interpretative phenomenology. Interpretive or hermeneutic phenomenology is an interpretation of human beings, and as human beings are essentially self-interpreting, interpretation is the proper method for studying human beings (87). The goal of Heidegger’s hermeneutic phenomenology is different to eidetic phenomenology in that it aims to uncover the hidden meaning of a phenomenon that is not immediately manifest to our analysing and describing (85), hence the interpreters have to go beyond what is given directly.

While the purpose of descriptive phenomenology is to describe the general characteristics of a phenomenon, interpretive phenomenology aims to understand and interpret the experiences of individuals (91). Therefore the methodological framework of this study was based on interpretive phenomenology in order to address the research objective, which is to better understand the experiences of individuals living with HIV accessing dental care.

Phenomenology as a Methodology

The philosophy of phenomenology has been employed in guiding research in multiple ways. Various schools have developed different approaches in phenomenological research (88). The Dutch School or the School of Utrecht University combines descriptive and interpretive phenomenology (85). Van Manen, a Canadian educator who has been widely cited in health literature, has written many helpful texts on explaining the Dutch school of phenomenology (81, 85). Van Manen’s work includes descriptive elements of Husserl’s phenomenology with a focus on studying lived experience before it has been theorized, but he also recognizes phenomenology as an interpretive process, in which the researcher makes an interpretation of the meaning of lived experience. Like Heidegger, van Manen does not embrace Husserl’s idea of bracketing and states that an interpretive approach to phenomenology means that it is impossible for the researcher to become fully separated from the text (81, 86): “ if we simply try to forget or ignore what we already know, we might find that the presupposition persistently creep back into our reflections” (93).

Phenomenology is fundamentally a philosophical discipline. Nevertheless scholars of the Utrecht School are generally interested in doing phenomenology in the service of their academic disciplines and for the purposes of understanding the practices of everyday life. Van Manen calls this pragmatic and ethical concern of how to act in everyday relations and circumstances "the phenomenology of practice". The effect of phenomenology of practice in our personal and professional lives lies in the reflective and formative aspects of phenomenology. Phenomenology of practice creates a potential for generating formative relations between who we are and how we act and between "thoughtfulness and tact" (94). Similarly in health sciences, phenomenological research is done to contribute to a more thoughtful practice of health professionals. Understanding the meaning of illness is crucial in patient care and it is vital for healthcare practitioners to gain an understanding of how the disease is experienced by the patient. Phenomenological research can be a valuable tool to healthcare practitioners because the practice of healthcare does not only require theoretical and pragmatic skills, but also reflective and philosophical insights. Phenomenological research in the field of health sciences is generally done by health scientists who are specialized in their own disciplines yet have less strong grounding in philosophical thought. Therefore, van Manen talks about making phenomenology accessible to those who are not professional philosophers with an extensive background in phenomenology (84, 94).

For the above reasons and as a healthcare professional and researcher who is fairly new to the world of phenomenology, I found van Manen's phenomenology of practice appealing to me. Van Manen's method is a context-sensitive form of interpretive enquiry of pre-reflective experience that has been very useful in very sensitive research areas in understanding people and difficult life situations (94, 95). Therefore, it is particularly suitable for understanding a sensitive topic such as the experiences of people living with HIV. Moreover, one of our goals in this study is to cultivate appropriate behaviours through a sensitive understanding of PLHIV in dental practitioners. And according to van Manen, phenomenology of practice is suited to serve practitioners who might be oblivious or insensitive to the depth and subtleties of other people's experiences in their daily practice, since experiential stories provide opportunities for evoking and reflecting on practice (94, 96).

Consequently, the methodological framework of this interpretive phenomenological study draws heavily from the work of van Manen. Phenomenological research is particularly challenging because it requires taking up or adapting a style or attitude of thinking as opposed to following a specific set of methods (93). Van Manen talks about phenomenology as a dynamic interplay between six research activities that allow flexibility in playing up or down one step or another depending on the emergent research needs. Although van Manen presents these six activities in the following order, he states that the researchers do not have to execute and follow each step and that the process of research involves working at various aspects intermittently or simultaneously (93):

1. Turning to a phenomenon that seriously interests us: phenomenological research is driven by a commitment to a question, a commitment of never hesitating to think a thought more deeply. A phenomenological finding is always an interpretation, which will never exhaust the possibility of yet another interpretation. In this sense, a phenomenological researcher should allow herself to be taken over by a quest and a deep questioning of something.
2. Investigating experience as we live it (rather than as we conceptualize it): responding to Husserl's call "Zu den Sachen" (to the things themselves), a researcher must turn to the nature of lived experience, which is the immediate pre-reflective consciousness of an experience. Lived experience is both the source and the objective of phenomenological research; we need to search everywhere in the life-world (the world as immediately experienced) for lived-experience material that might yield something about its essence upon reflective explication. "Phenomenological research requires of the researcher to stand in the fullness of life in the midst of the world of living relations and shared situations yet actively explore lived experience in all its aspects."
3. Reflecting on essential themes that characterize the phenomenon: The purpose of phenomenology is to understand the essential meaning of a phenomenon and asking ourselves reflectively "what is it that constitutes the nature of this lived experience". In phenomenology, there is a "distinction between appearance and essence", between this and that aspect of an experience and what gives an experience its unique meaning. The task of a phenomenological researcher is therefore to reflectively bring into grasp the meanings that tend to evade our understanding in our natural day-to-day viewpoint.
4. Describing the phenomenon through the art of writing and rewriting: As mentioned before, in the words of Heidegger phenomenological enquiry is about "to let that which shows itself be seen from itself in the very way in which it shows itself from itself; to

reflectively render the essence of a lived experience understandable and comprehensible. This bringing something to speech is most commonly done through writing. But writing is not merely a final step in the process of research, writing is our method. Writing our thoughts fixes them on paper and externalizes what is internal. As we look at our words our words look back at us, and thus writing creates a reflective stance that is necessary in doing qualitative research. The object of phenomenological enquiry is to produce a deep text, and a deep writing can't be produced in one session. Writing and rewriting creates depth, a consciousness necessary to phenomenological enquiry.

5. Maintaining a strong and oriented relation to the phenomenon: Conducting a phenomenological investigation is extremely demanding since the researcher must strive to maintain a strong orientation to the fundamental research question. Without this strong orientation, the researcher becomes vulnerable to wandering aimlessly and yielding to superficial speculations and self-indulgent reflections or to settle for presumptions or falsities.
6. Balancing the research context by considering parts and whole: Phenomenological research deals with the question of "what-ness" but the end purpose of the research is to construct a text. There is the danger that the researcher becomes so stuck with pondering the question that fails to reach the clarity necessary for writing an informative text. On the other hand it is not impossible to get buried so much in the writing that the researcher loses sight of where to go next. Therefore, the researcher not only needs to step back at several points and check how each part is contributing to the total, but also to constantly evaluate if the overall design of the study allows the parts play their role. Because there are no blueprints to follow in phenomenology, the researcher may not be able to anticipate what direction she needs to take. The resulting frustration could lead to something similar to a writer's block. So it is useful to have a structure or form for the study in mind, although the definite form will only emerge as the writing progresses. The solution Van Manen proposes is to keep in mind the "evolving part-whole relation of one's study" (93).

Method

Researchers using phenomenology are generally reluctant to prescribe techniques and specific steps in order to preserve the integrity of the phenomenon. However, according to van Manen this does not mean that phenomenology excludes the use of certain investigative techniques and methods, especially for those new to phenomenological research. Those who wish to practice phenomenology in professional contexts can seek help from empirical and reflective methods and procedures. Empirical methods are those research activities that yield experiential material, including personal description of experiences and interviewing for experiential accounts. Reflective methods refer to phenomenological reflections and analysis. The selection and practice of these empirical and reflective methods depend on the context and the nature of the study. The researcher should not treat these guidelines as recipes and should be flexible and creative in her thinking (84, 97). In this section the empirical methods to collect data and the reflective methods used to analyse data are discussed, as well as the ethical considerations. The six research activities described by van Manen (93), which constitute the methodological framework of this research, were used to guide and inform the empirical and reflective methods of this interpretive phenomenological study, throughout the research process.

Empirical Methods

Data in a phenomenological sense is human experience; hence data collection means constructing a text about the meaning of the human experience (85, 93). Data collection for this study was through conducting eight in-depth, semi-structured, open-ended interviews using an interview guide. Interviews are an important means of collecting data in qualitative research (85). Interviews can yield a variety of data including narratives, which are particularly useful in interpretive phenomenology (85).

Sampling Research Participants

For this study we used purposive sampling, namely criterion sampling. Purposive sampling is a non-probability method of sampling, widely used in qualitative research. There is no one ideal sampling strategy in purposive sampling since the sampling strategy depends on the objective of the study. The researchers might employ a series of strategies depending on the context and their judgement (98). The participants of a phenomenological study should be selected to be individuals who have experienced the phenomenon sought by the researcher, in order to build a rich understanding of the phenomenon (81, 99). For this reason we employed "criterion sampling" which involves looking for participants who meet a certain criterion (98), in this case having the experience of accessing dental care as a person living with HIV. Interpretive phenomenological studies are generally conducted on a relatively small and reasonably homogenous sample size (100). There is no rule about the number of participants in phenomenological research (97) but Creswell suggests collecting data from five to 25 individuals (81).

Therefore, we sought to recruit six to ten individuals who met these criteria: (i) living with HIV/AIDS; (ii) living in the greater Montreal area; (iii) over the age of 18; (iv) able to speak English; and (v) having tried accessing dental care in the last three years. We sought to interview individuals residing in Montreal for convenience but also for a more homogenous experience of accessing dental care. Also we excluded individuals whose last visit to a dentist was more than three years before the interview because we speculated that it might affect the participant's ability for providing detailed descriptions of his experience.

However, as is the nature of qualitative, particularly phenomenological research, our sampling strategy was flexible corresponding to our research needs. For example, after being able to only recruit male participants for our first five interviews, we tried recruiting a female participant in order to have a female perspective on the topic. That being said, unfortunately we were unable to recruit any female participants in the timeframe of this research project. Another important factor in determining sample size in phenomenological research is the depth and richness of individual cases (97). On this account, after conducting seven interviews, we revised our data and our preliminary analysis and concluded that in order to respond to our research question we would need a particularly rich interview. Therefore, we were looking to recruit a participant with several and various encounters with dental professionals. After interviewing the eighth participant we concluded that we had collected enough rich and meaningful data to stop data collection and proceed with data explication.

Recruiting Research Participants

We used several strategies to recruit potential participants for this research. Recruiting participants for in-depth interviews can pose difficulties to researchers, especially in the case of sensitive topics and hard-to-reach samples, such as in the case of PLHIV (101). One strategy to overcome this challenge is to recruit through organizations with the help of key contacts in the communities (101). Our research partners, especially Daniel Lanouette, who is the coordinator for group services at ACCM, turned out to be indispensable in locating and recruiting potential participants. After an initial meeting and several email exchanges with our co-researchers, several recruiting strategies were put forward and we decided that the best strategy was trying to recruit participants in person. First, Daniel invited me to one of the regular meetings held weekly at ACCM. I talked to the people who attended the meeting and briefly presented our research goals and procedures and invited the members to engage in a discussion over access to oral health. Then I distributed copies of the consent form as it provided an overview of the research, and offered to provide more information. A copy of the consent form can be found in the Appendices of this thesis. Those who were interested in participating were asked to meet me at the end of the session or to contact me. The first two participants were recruited in this manner. After this initial meeting other recruiting strategies were discussed with the rest of the research team, especially with Daniel who was present at the session. Daniel Lanouette suggested that he could locate and recruit potential participants. Since he was already familiar with the community members and it was easier for him to establish trust, we decided to try this strategy. It proved to be effective as four of our participants were recruited by Daniel. Daniel talked to members he thought might be willing to participate and approached them. He then invited the ones who agreed to an interview to contact me or asked whether they preferred to be contacted by me. After establishing the contact, I explained the research objectives to the potential participants again and after verifying whether they fit the inclusion criteria, we arranged a date and a place that suited the participants. I also paid several visits to the community centre, where I conducted most of my interviews and talked to the members about my project and invited them to participate; one participant was recruited in this manner. The demographic data of the research participants is summarized in a table and can be found at the end of this chapter (Table 1).

Conducting Conversational Interviews

The purpose of doing a phenomenological investigation is to, in a way, "borrow" the experiences of other people of a phenomenon in order to gain a deeper understanding of the meaning of that phenomenon (93). There are two main techniques to obtain the lived experience of a phenomenon from another person: conducting face-to-face interviews or asking for a written account (93, 102). We selected interviewing because we sought to collect a more complete, detailed and nuanced description of the experiences (102). Although systematic data collection such as interviewing is rarely done in philosophy, in professional fields experiential accounts from other people can provide the phenomenological investigator with rich experiential material (84). However, the interview in an interpretive phenomenological study is not only a means for collecting and exploring data, but it is also used for establishing a conversational relation with the participant (93).

I conducted in-depth semi-structured interviews with each participant. Semi-structured interviews enable the researcher to engage in a dialogue with the participants and are flexible enough to allow original and novel themes to emerge and be further explored by additional questions. Conducting a semi-structured interview does not mean that it is necessary to prepare a dozen questions before an interview. Being overly prepared could result in the investigator leading the participants instead of facilitating the interview (103). During an interview the researcher needs to be both present to the phenomenon under investigation, as well as to the person being interviewed. Instrumentation could disrupt the presence of the researcher in the interview and the participant-researcher relationship that is so important in phenomenology (103). Nevertheless, it is important to have a plan for the interview, in order to facilitate a natural flow of the conversation (97).

The questions asked to the participant should focus on the description of the experiences of the specific phenomenon under study, the remaining questions asked are follow-ups based on the responses of the participant (103). Before starting with the interviewing process we devised an interview guide. This interview guide included a few key questions in an open and expansive format to encourage the participant to talk at length, as well as probing questions to assist the participant with recalling past experiences or additional information. While I was thinking about the interview guide, it was important to refer back to van Manen's six research activities and his suggestion to maintain a strong orientation to the phenomenon; in other words all the questions had to be in line with the investigated phenomenon (93). During conducting a preliminary literature review and reflecting on the research questions and objectives, I came to the conclusion that in order to have a profound grasp of the experience of accessing dental care for PLHIV, one needs to understand what it means to live with HIV and the experience of HIV stigmatization, especially in healthcare settings. The concept behind devising the interview guide was to first start with the most general questions such as the experience of living with HIV in general and move into more detail regarding their oral health as the interview progressed. The more sensitive questions such as the ones regarding discriminatory behaviour and HIV stigmatization were left for later in the interview, once a certain level of rapport and trust had been established. I used pre-existing conceptual frameworks found in the literature (104, 105) for the HIV stigma related questions. However, during the interview process I tried putting less emphasis on these questions and mostly used them as probing questions to avoid the possibility of leading the participants. We also added a section about the ideal dental setting because dental professionals could use the opinion of PLHIV about what constitutes an ideal experience at the dentist's as suggestions and guidelines to provide better services to these patients. Our co-researchers revised this interview guide to ensure that the questions were relevant and sensitive. This final draft of the interview guide was intended to be used as a rough plan. I had to use my judgement and adjust the questions according to the natural flow of the conversation and the research needs with each interview. A sample interview guide could be found in the appendices (Appendix B).

All interviews were done in English in a period between April to November 2016. After establishing initial contact with each participant, I invited them to meet in a setting that suited them best, such as a quiet room at ACCM or the Faculty of Dentistry at McGill, or other locations that the participants suggest, such as their workplaces or cafes, as long as a confidential discussion could be done. Consequently, two of my interviews were done in a private room at the faculty, and the rest at ACCM. Before the beginning of each interview I had an informal warm-up chat with the participants, offering them a beverage, in order to establish rapport and prepare them for discussing sensitive issues in an informal and conversational manner. Then I moved on to explain our project once more, as well as the procedure of the interview, and their rights as research participants to refuse to answer any question or stop the interview at any time, and the steps we would take to ensure confidentiality. I handed them a consent form (Appendix A) containing all this information to read and invited them to ask any questions they might have before signing the form. The consent form was approved by the Institutional Review Board (IRB) of McGill University. I recorded the interviews using both a phone and a laptop. I informed the participant when the recording was about to begin and stop. I did not take notes during the interview as I thought it does not fit the conversational nature of the interview and that it would disrupt my mindfulness and engagement in the conversation. Instead I took notes of things that I thought were important to our research immediately after the interview. At the end of the interview I asked the participants if they wished to receive a copy of the interview transcript to ensure an accurate representation of their words or to add or remove comments if they wished to (however, all of the participants said that this was not necessary).

During the interviewing process it was important to refer back to van Manen's six components of interpretive phenomenological research (93) that was used the methodological framework of this study. One of these components is to investigate experience as it is lived. According to van Manen, the aim of collecting material is to collect minimally interpretive descriptions that are as close as to the lived experience as possible (93). Naturally every description is already an interpretation but there is a difference between descriptions that are experiential and descriptions that are opinions and perceptions. Therefore, one challenge of phenomenological enquiry is to try and gather vivid experiential accounts. Van Manen recommends that when the participant's recounts becomes too general, the discourse should be brought back to the level of concrete details (84, 93). However, most PLHIV have had a long time to reflect on their experiences as a human being living with HIV, they had to redefine and reinterpret not only themselves but their role within the society based on the experiences they have went through. Perhaps this is why I found that in several occasions my participants had the tendency to provide post-ontological interpretations of their experiences as opposed to concrete details. That was one challenge in my research. In many cases I found myself having to ask for examples and details.

Also as a part of his six research activities, van Manen advises the investigator to maintain a strong orientation to the fundamental research question. Although it is tempting to jump into the interviewing subjects using open-ended questions, it is important not to let the method lead the question (93). At the same time that I was trying to carry a relaxed and open conversation with my participants as being mindful in listening to them, which is necessary for truly engaging in any conversation, I had to be mindful and ask myself if the data provided by my participant, albeit very interesting, was relevant to the research question. On several occasions I had to interrupt my participants and bring them back to the track. However, I had to do that in a way that did not disrupt the established rapport, by saying for example “this is quite interesting, I’d like you to tell me more after the interview”. Of course, sometimes I decided to not interrupt the participant if I thought at the moment that what he’s saying could lead to something relevant to the research question, or that listening to the participant helped with establishing trust and rapport needed to discuss sensitive issues. This could explain why some of my interviews were longer than average. In general, the interviews lasted between 50 minutes to a little over than two hours.

Data Storage

The next step in preparing a recorded interview for analysis is to transcribe it word for word. Transcribing may seem like a technical task but it is the first step of data analysis in qualitative research (106). It is therefore advised that the researcher does this process herself because transcribing facilitates the transition to the data analysis phase and gaining a better understanding of the phenomenon (103, 106). Transcribing was a time consuming and occasionally exhausting process for me but it was a worthwhile step in getting into an interpretive frame of mind. It was important to transcribe an interview as soon as possible; this helped me with recalling words or comments that were not comprehensible in the audio, and the nonverbal cues such as facial expressions and body language. The number of hours to complete transcribing varied greatly between interviews, but on average it took almost 3.5 hours to transcribe one hour of recorded audio. I used a transcription software, Express Scribe, which allowed me to control the speed playback and boost the volume of the recording. I first transcribed each segment using the software to slow down the playback speed, and then went over each segment once more with the normal speed to correct the possible distortions as a result of changing the playback speed. Finally I listened to the interview as a whole once more while reading the transcript and correcting mistakes and misspellings. Transcribing is an interpretive process that involves judgment making about how to present the data into written form (106). As I transcribed more and more interviews I became more comfortable about how much detail (general demeanour, tone of voice, crying, laughter, pause, etc.) to include in the transcripts.

During transcription I read and re-read each sentence and reflected on the possible themes, as well as my own interviewing skills and made notes of my reflections. I also noticed the different effect of transcribing each interview on myself; for example some interviews were emotionally draining to transcribe while the others were easier to listen to and to type up. This made me reflect on my own stance and biases as a researcher (as well as an individual). At this stage I had started writing reflective memos.

Measures were taken to protect the confidentiality of the participants in transcribing and storing data. The typed material did not contain any names; as I was transcribing I replaced the identifiable name with initials or pseudonyms. Each interview transcript was assigned a number and filed via numerical codes in lieu of respondent's names on my computer. The data was stored on my computer – accessible only with a password into a password-secured folder, which is to be destroyed after one year. The printed material including consent forms was stored in a locked filing cabinet.

Reflective Methods

The purpose of phenomenological reflection and explication is to understand the essential meaning of an experience, as opposed to a pre-reflective lived understanding of what that experience means, which is a laborious and difficult task (93). I use the term explication here instead of analysis since the term analysis means breaking into parts, therefore implying a loss of the context of the whole (99). The reflective part of my study was on-going all through my research and started before data collection. As phenomenology does not follow a strict method and is rather based on philosophy, it is crucial to coherently apply the philosophy of phenomenology in data explication (103). Consequently, I was reading phenomenological texts such as the works of Gadamer, van Manen and Heidegger, as well as phenomenological research done in health sciences to familiarize myself with the philosophical underpinnings of phenomenology and to take in a phenomenological way of thinking. I took time to read and learn about fundamental philosophical methods of phenomenological enquiry, phenomenological reduction, and incorporate it into my research.

Phenomenological Reduction

Reduction is central to the phenomenological study of lived experience. To arrive at an understanding of the essential structure of something, we have to reflect on it by practicing reduction. Therefore, I will dedicate a section of my thesis to explain my understanding of reduction and how I incorporated it into my research.

The concept of phenomenological reduction is complex and articulated in many ways in the literature. According to van Manen, reduction is a continual reflexive effort to lead back (reducere) to the way in which a phenomenon is experienced before the experience is conceptualized or theorized. Experimental reduction compels the investigator to adopt a critical reflective attitude, to stay clear of theorising and generalisation, and to remember that phenomenological enquiry is continually directed towards the lived experience. Reduction is traditionally seen in conjunction with epoche or bracketing, but reduction does not mean that the investigator must bracket the phenomenon away from the world. Rather, the researchers need to reflect about their pre-understanding and biases that seems to impinge on their perspective. Of course this doesn’t mean that the researcher should expect to gain a completely fresh uncontaminated perspective. It means that instead of covering a given aspect of the phenomenon with a specific frame of meaning, it should be explored carefully, layer by layer, to uncover its original source. In the end, the investigator should be aware that any experience is more complex than any construct of meanings can reveal, and phenomenology only offers a way to better understand a phenomenon (93, 95, 96). In other words, “The phenomenological reduction teaches us that full reduction is impossible, that full or final descriptions are unattainable” (93).

Keeping in mind that gaining a purely descriptive gaze free of any pre-understanding is impossible, my application of the phenomenological reduction involved taking up an open yet critical reflective attitude. Open in the sense that I tried to remain receptive and reflective to question my assumptions and understandings. And critical in the sense that I assumed a critical and tentative towards the emerging interpretations and presentations of the lived experience and kept asking what I am really seeing. My phenomenological enquiry was a continual reflexive effort to get back to our research question and ask myself: “is this really what the experience of receiving dental health care is for a person living with HIV?” Since writing was my main method of understanding and describing the essences of the lived experience, the process of phenomenological reduction was mainly present in the process of writing and rewriting my findings, which made me reflect on my interpretations and put them into question.

Isolating Thematic Statements

The next step after phenomenological reduction in data explication was to delineate units of meaning and cluster them to form themes (99). Data analysis or explication is basically the process of determining what the themes are (93). Meaning is multidimensional and multi-layered. In order to grasp and clarify the structure of meaning in a text, it is helpful to think of the phenomenon described in the text in units of meaning, or themes. It is important to understand that phenomenological themes are not categorical statements or generalizations. They are means by which we could navigate and explore the meaning of lived experience. A theme describes one aspect of the structure of lived experience. Formulating a thematic understanding is not a rule bound process but a free act of seeing meaning (93). Although the reflective process of my research had started long before, I began isolating the essential themes after having collected three interviews. Van Manen suggests three approaches to uncover or isolate themes in a given text (93):

1. The selective or highlighting approach, in which we listen to or read a text multiple times and ask what phrases seem particularly essential about the experience being described, we highlight or underline these phrases.
2. The wholistic reading approach, in which we look at the text as a whole and ask what phrase captures the meaning of this text as a whole, and we try to express meaning by formulating such a phrase.
3. The detailed or line-by-line approach, in which we look at every sentence or sentence cluster and ask what does these sentence reveal about the phenomenon.

In the first stage, I used the selective approach. I listened to the first three interviews multiple times, and read and re-read the text, highlighting the sections that seemed to carry significant meaning about the experience. At this stage I had not yet started to try and capture the essence of emerging themes with appropriate words or phrases. I looked at the texts in whole, trying to immerse myself in each interview, and thought about what phrase or word encapsulates the essential meaning of each person's account as a whole. In order to I started the highlighting approach, where trying to discern the themes that began to emerge, what was significant about each interview. Then I proceeded to read these three interviews line by line and ask what each sentence reveals about the experience. This stage helped with identifying keywords or concepts that could be potentially useful for describing themes and subthemes, and also with redefining and refining the initial units of meaning. I drew multiple mind maps in order to refine and cluster these units of meaning to form themes. I noticed that certain experiential themes recurred as possible commonalities in various descriptions, so I had to hold on to these themes by capturing them in singular thematic statements. After initial theme isolation for the first three interviews, I proceeded to collect more data. With each additional interview I kept rewriting and revising my initial findings, as I transcribed.

Once I was finished with the data collection I went back to three particularly rich interviews and listened to them multiple times again, and analysed them using the detailed reading approach, trying to capture essential keywords and concepts that were found to be common between the interviews. I then applied the wholistic reading approach once more to all the interviews, trying to summarize each interview in a way that it incorporates the potential themes and subthemes, as I kept modifying the findings. This step was also served as a validity check of the potential themes (99). In this way I became part of an “interpretive circle” moving back and forth between interpretations of the whole text and the details that came as significant in a given reading. This is similar to what van Manen suggests as balancing the research context by considering the parts and the whole, as a part of phenomenological enquiry (93). As the new details changed the overall interpretation, which in turn lead to new details standing as significant, the interpretive circle led to a richer and richer understanding of the text (87).

At this stage I had identified three main themes, each with their own several subthemes, in the transcripts but these findings were by no means finalized. I proceeded to determine if the emerged themes were essential to the experience of accessing dental care for PLHIV, and not incidentally related with it. To do so, I asked myself: “is this theme a quality of the experience that makes the experience what it is, or could I change and remove this theme without it making a difference?” (93). At the same time, I held collaborative discussions on the themes and thematic descriptions with my supervisors, as well as one of co-researchers who was also a participant. In this “collaborative analysis” (93) the identified themes were examined, and reformulated and I was able to test my work and reflect more on the findings.

Writing and Rewriting

Lastly I tried to produce a phenomenological text, which is the object of phenomenological research. Writing is not merely a last stage in phenomenological research; on the contrary, phenomenology as a research method is mainly an act of writing (93). For the most part, research activities applied in the research process including the interpretive circle, phenomenological reduction, and reflexivity were primarily done in writing. It is not possible to maintain a strong oriented relation to the phenomenon and to reflect on the essential themes and to describe them without writing. Writing and rewriting was particularly key in the reflective process of the study, from organizing my interpretations of the participants' narratives into themes, to careful selection of the words to describe the themes and the findings of this study. Also because there is no fixed definite research outline to follow in phenomenology, the decisive structure of this study only started to emerge as I progressed with my writing (93).

The writing part was also one of the most challenging parts of this research, as I repeatedly experienced something similar to a “writer's block”. I use the term “writer” because writing phenomenological text could be similar to creative writing. In hermeneutic phenomenology not only what the text says, but also how the text says it are important. This is because a good phenomenological text can make its readers see meaning in a manner that enriches their experiences and provides them with insights (94, 96, 107). Similarly, one of our research aims was to enrich perspectives of dental practitioners and students and to contribute to their reflective understanding of the everyday experiences of their HIV positive patients, hoping to eventually affecting their treatment of these patients. So while writing my purpose was more than just to report results, I aimed to write my findings in a way that could evoke understanding and reflection. Thus I tried to construct an anecdote around my themes and then draw narratives from the interviews to support this anecdote and to present my readers with the subjective interpretation of PLHIV of their experiences.

Rigour and Trustworthiness

Although there is a lack of consensus regarding rigour in qualitative and interpretive research, researchers conducting phenomenological studies need to ensure the trustworthiness and credibility of the enquiry (92, 108). Credibility is defined as “the quality of being trusted and believed in” (109). To achieve credibility, I tried to present my findings in a way that people reading this presentation could recognize these experiences and identify them as their own (92, 108). This is known as the phenomenological nod and seeking this phenomenological nod is one way of verifying rigour (110). To achieve this, I shared and discussed my results with my supervisors and our co-researchers, especially Daniel who was also a participant in this study. I also sought to establish trustworthiness by clearly describing the research procedures in a way that the readers could audit the steps taken in the research process (81, 92, 108). Moreover, I demonstrated how each step and the whole interpretive framework were informed by the research paradigm and the research questions. This activity is central to the trustworthiness of a study (108).

I dedicated many hours to studying the philosophical underpinning of phenomenological research and to presenting it in my research, which contributes to the strength of a phenomenological research (111). This included making reference to the most key features of phenomenological research such as bracketing and reduction, since no work could be considered phenomenological reduction is not somehow included and introduced in it (111). Several research activities I took in the reflective phase of the study adds to the rigour of this study. This includes applying reflexivity and reduction, as well as writing and rewriting to arrive at a vivid and faithful interpretation that reflects the complexity of the lived experience of PLHIV (92). And as a step in isolating themes I summarized all interviews, which allowed me to do a validity check of the emergent themes. Moreover, in line with van Manen’s proposed six research activities, I tried to maintain a strong and oriented relation with my research question. I found this particular activity to be especially beneficial to the rigour of a phenomenological study. Phenomenology could be extremely demanding of its practitioner because it is easy to indulge in preconceptions or thrown together interpretations (93). Therefore, I had to be my own most strict critique, to keep stepping outside of my research and question my perspectives and my findings, which I believe adds to the trustworthiness of our research.

Reflexivity and Positioning Myself

In qualitative research it is understood that the researcher will inevitably influence the context of the investigated experience and the direction of the findings through her actions and decisions (112-114). Reflexivity is the active acknowledgement existence of this researcher bias and a self-aware analysis of the role of the researcher within the research process (112, 114). Reflexivity is central in qualitative research and a major means of adding credibility and rigour to a study (112, 113). Depending on the research paradigm, reflexivity can be adopted in a variety of ways (114). In phenomenology it's argued that every researcher understands a phenomenon differently, because each person brings her own fore-understanding and historical background into the research (108, 114). So in phenomenology reflexivity involves an evaluation of the researcher's own experiences and pre-understandings (114).

I was reflexive through all the steps in this research, from devising the research question and data collection to writing and reporting my findings. For me reflexivity involved constantly considering my role as a dentist and my own biases and preconceptions of what it means to live with HIV, and how my status as a dentist might affect my interpretations and actions and that of my participants. Due to my status as an outsider, and also the sensitive and vulnerable condition of my participants, I had to be extra cautious of the power imbalance. I was aware that not only I'm an outsider to the group, I was a dentist trying to understand how PLHIV perceive dental care and my fellow dentists. In addition to the possibility of my status as an outsider and as dentists might affecting the responses of the participants, before conducting the interviews I was mainly exposed to the perceptions of dentists and healthcare professionals of what it means to live with HIV. However as a healthcare practitioner and formal student, I had an advantage of witnessing the fear of HIV transmission among my colleagues after incidents such as needle stick injuries on one hand, and their sense of professional ethics and empathy managing "high risk" patients on the other. Moreover, not having lived with a chronic condition or having experienced a serious illness in my life, I was aware that I had to relate to and empathize with experiences of illness quite different from mine. That being said I found myself surprised by how much the experiences of PLHIV resonated with me and thinking about what made these experiences familiar to me was one of the keys to the unlocking what it is that constitutes the essence of their lived experience. In other words, I began to understand the experiences of my participants through the lens of my own experiences. Throughout the researcher I noticed how my own perceptions and interpretations were constantly changing, both from being exposed to lived worlds and experiences of my interviewees as well as being familiarized with phenomenology and a phenomenological way of thinking. I was not only aware of my role and status, but of my weaknesses and strengths as a researcher, particularly during interviews and later during data explication. After each interview, and especially while transcribing, I tried to step outside and observe myself and my interviewing skills and see what challenges I faced and which one of my particular behaviours and attitudes worked best. For example I noticed how I could not engage in a conversational interview and be completely present unless I was relaxed and followed the guide flexibly. I practiced reflexivity through keeping logs discussing with peers and supervisors.

Research Ethics Consideration

This study was conducted according to the ethical principles stated in the declaration of Helsinki (115). Ethics approval was obtained from the McGill Institutional Review Board before the start of the research project. Prior to taking part in the study, all participants read and signed an informed consent form, outlining the interview process and including the contact details of the researchers and the ethics committee. They were informed of the expected time commitment and the potential benefits and risks of the study. The risks inherent in this project were predicted to be very low. However, I prepared myself to be aware and responsive to situations where participants experienced some negative emotions during the interview since HIV is a sensitive topic. I ensured the participants that they could decline answering any questions and opt out of the study at any time without any consequences.

All measures were taken to protect the confidentiality of the participants. All interview recordings and transcripts were transcribed by me and filed via numerical codes in lieu of respondents' names on my computer, in password-secured folders. The typed materials do not contain any names. Any identity will be kept confidential via the use of pseudonyms in any presentation and/or publication. Any printed material including consent forms will be stored in a locked filing cabinet in a secure central location accessible only to the principal investigators. There were no conflicts of interest to report and no compensations were provided to the participants.

Table 1. Socio-demographic characteristics of the participants.

Characteristics	**Categories**	**Number of participants (n=8)**
Gender	Women	0
	Men	8
Place of birth	Quebec	6
	Other Canadian provinces	1
	Other countries	1
Age	41-50 years	4
	51-60 years	4
Time living with HIV	10-20 years	3
	21-30 years	3
	>30 years	2
Highest level of education	High school	1
	College (CEGEP)	2
	University	5
Occupation	Unemployed	4
	Student	1
	Part-time	1
	Full-time	2
Dental insurance	University insurance	1
	Public insurance (welfare)	4
	No insurance	3

4. FINDINGS

When I embarked upon this research project, my goal was to tell a story, the story of a person living with HIV who seeks dental care. My intended audience to read the research findings were mainly dentists and dental students such as myself. I wished that they would read this story and begin to contemplate and understand how a person living with HIV experiences dental health care. I was hoping that perhaps the readers would even recognize and relate with some aspects of the experiences of PLHIV- hoping that such deep understanding and empathy would affect the perceptions and consequently the behaviours of the readers towards HIV positive patients.

Let us imagine an individual who is living with HIV in Montreal sitting on the dentist's chair; the dental professional who is attending to him has two main elements to consider. The first aspect of providing dental care to a patient is naturally the dental health of the patient, and the second aspect is the human element of providing dental care, which is the dentist-patient relationship. Therefore, we are going to look into the lived experience of accessing dental care for an individual living with HIV from two general perspectives. First, we are going to explore what health, specifically dental health and health issues meant to our participants. Second, we are going to consider at how the participants experienced their interactions with dental and healthcare staff and the challenges they face that are specific to PLHIV. An overview of the findings is presented in Figure 1, which can be found in Appendix C.

When I started with the reflective part of this study I realized that although the story in this study begins with the participant seeking dental care, it is only through appreciating the general context of living with HIV that we can truly begin to understand the specific experience of receiving dental care for PLHIV. While the meaning of living with HIV is a complex and sensitive matter that falls beyond the scope of this study, I will try to provide the reader with a more general context as I explore each theme, at the same time trying to remain oriented towards the research question, which is specifically about the experience of PLHIV with dental care.

Oral and General Health

> "*[What does it mean] to live with HIV? Well it means that I live with a chronic illness, a chronic infection.*"

Living with a chronic illness constitutes a substantial part of the experience of living with HIV and it affects the individual from all angles. Firstly, and simply, a person living with HIV is constantly struggling with his health. Secondly, the struggle with health forces limitations and challenges to the individual in his personal and professional life. Thirdly, the health problems pose a constant source of worry and anxiety to the person. Finally HIV affects the individual's general attitude towards his health and its management. In the following sections I am going to elaborate on each one of these aspects.

The Struggle with Health

> *"I think another difficulty to my life for many aspects [...] So it is not the only difficulty I have in my life but it contributes."*

The first time I asked a participant to tell me what it meant to live with HIV he presented me with the above response. Living with HIV introduces constant struggle and hardship that is present in all aspects of the person's life. To struggle has been defined as "having difficulty handling or coping with something" and to "strive to attain something in face of difficulty or resistance" (109). For every human being life is a constant struggle; we all struggle to cope with various obstacles, anxieties and loss, and to strive to adapt. HIV adds an additional layer of struggle to what is already difficult enough. In the words of one participant: "*life's hard for everyone you know, and that [HIV] makes it a little bit harder.*" Living with HIV means that in addition to all this, the individual has to face a sudden change in his existence and his sense of self introduced to his life by HIV, a deteriorating health that challenges his personal and professional life, and the obstacles and limitations associated with HIV.

Perhaps struggling with hardships was most evident in the narratives of the participants when they talked about their health: to live with HIV is a constant struggle with health. First of all, the participants dealt with numerous and varied health issues. Two of them had experienced their health condition become so severe because of HIV that they had to be hospitalized. They suffered from pneumonia and paralysis and one of the participants was even starting to develop

AIDS before he got on HIV medications. All the participants were taking HIV medications at the time of the interviews, and their CD4 count and viral load were under control. Paradoxically, they believed that it was the HIV medications that currently caused the main health issues suffered by many PLHIV, from heart problems to internal organ failure to palsy. As one participant told me, "*even if you don't get sick it's still no picnic, it's no picnic, there's side effects from the medications*". The following quotation is an example of a participant's struggle with the side effect of his HIV medication, in this case maldigestion, and the way it interferes with his daily life:

> *"I don't digest very well because of that, so I need to take a first medication when I wake up, a half hour before I take food and this medication is blocking some enzymes that would cause me to have like a heartburn and things like that because of my HIV medication, so take this and the enzyme is blocked so after that I can take my medication to digest. I feel like the digestions is one of the worst side effects for you."*

On top of the HIV and the side effects from the HIV medications, some participants were struggling with additional health problems such as infections, diabetes, HCV, smoking, and drug abuse that contributed to their poor health. A few participants shared that at one point they had suffered from mental health issues, which they considered as crucial in the course of their lives, influencing their relationships, careers, and their healthcare seeking behaviours. It is no wonder if such constant struggle takes its toll on the individual, as demonstrated in this quote by one of the participants:

> "*I'm tired, or I feel I'm more fragile, I feel like my capacity to cope with stresses is less than other people my age that are not living with HIV.*"

If we take a closer look at this quotation, it is hardly surprising that the participant felt "tired" or "exhausted". After all, as another participant succinctly phrased it, just to take care of himself was "*like a part-time*", and this "job" consumes energy and resources. In this quote the participant talked about feeling "fragile". The word fragile means liable to break (109); there is a sense of vulnerability as well as uncertainty about this word, and about the participants' narratives related to their health. The participant felt he was more liable to yield to stress and that his health was unsteady: he had "*bad days and better days*". He compared himself with others his age and felt "prematurely aged": "*I'm getting older, and when I read things that people living with HIV, their health is more like the health of a person ten years older I kind of feel that* *sometimes*". The notion of aging does not necessarily carry a negative weight, but in this sense it signifies a deteriorating health and thus less resilience and coping ability. Everyone goes through the process of aging and the health problems associated with it, but HIV perceptually accelerate this process.

Similar to their general health, the participants were experiencing a constant struggle with their oral health and found their oral health problems persistent and exacerbating. A participant told me "*I think I have more cavities than before. Every time that I go I have cavities and cavities.*" Although the participants attributed this condition to many factors such as poor oral hygiene and diet, smoking, diabetes, and drug abuse, almost all of the participants believed that HIV played a major aggravating or "accelerating" role. Most had experienced the adverse effects of HIV and the HIV medications on their oral health in multiple and various ways. Their oral health issues included dry mouth and changes in saliva, which they considered as an underlying factor for many other problems, as well as dental issues such as cavities and teeth loss, oral diseases such as thrush, halitosis, and particularly periodontal problems such as bone decalcification, receding gum, tartar build-up, and thrush. Additionally, some participants suffered from aggressive and recurrent gingivitis that was difficult to treat:

> *"For few years I had gingivitis all the time, like I would get it two or three times a year, pretty serious gingivitis. And that was really unpleasant, and it was really difficult to get rid of also, so I count HIV probably for this."*

These oral health issues in turn created additional difficulties for the participants. One of them experienced a persistent gingivitis for a long time that impeded his social and personal life, as he found it difficult to get close to others because of the bad breath caused by gingivitis:

> *"Well it's social life, and I need to be even more careful so I'm not- now it's a little less, but doing on a regular basis gingivitis gives you bad breath and you don't want to talk to anyone or be close to anyone, so it's isolation and trying to get rid of this, it's difficult to be in public or having a personal life also being close to anyone. So it's affecting me this way."*

Some participants faced difficulties with their most routine bodily functions because of their poor oral health. For instance, one felt unable to chew after losing his teeth. Another avoided chewing on one side of his mouth because of cavities on the other side; he also had to be careful with what he ate because his teeth sometimes broke. A third participant had difficulties swallowing after having lived with HIV for a long time: "*I find my swallowing is a bit different than it was, I find it's a bit more- now I feel it you know. Now I can feel the swallowing more"*. Normally, one does not need to be careful with or even mindful of actions such as chewing or swallowing. Therefore, the struggle with (oral) health was experienced by some participants as an awareness of their body and bodily functions, or rather its impairment.

In addition to the somewhat unsurprising effect of poor oral health on function, the participants experienced more subtle layers to their struggle with oral health. I'm going to cover some of these key aspects with a particularly rich quotation from one of the participants:

> *"I don't think I had a lot of pain due to it, I guess it's more insecurity of, well you're getting to the point that you're, am I going to have a denture? And that's very hard for your personal image or you know what you think about yourself because having teeth is you know- losing even one two that you lose is hard. You know it's something you lose."*

At this point in the conversation the participant was telling me how his struggle with oral health had affected his whole life. Firstly, he had feelings of "insecurity". Most participants shared similar feelings of discomfort about their oral health (and we will expand on it under the subtheme "anxiety" in the next section), but this specific quote is interesting in showing that the "insecurity" or the discomfort from anticipating something unfavourable could surpass the actual physical discomfort or "pain". Furthermore, in this quote he revealed his struggle with personal image associated with oral health. This finding was not limited to one participant; a few shared similar experiences of difficulties with their self-image or concerns about being judged by others due to their oral health, particularly the appearance of their teeth. As *"people will judge other people because of how their teeth look"*, no wonder that a person struggling with his oral health could also struggle with his personal and social image and self-esteem.

Last but not least, this participant uncovered a noteworthy component of his struggle with oral health, experiencing loss. He emphasised on how losing his teeth was about "losing something". As often the case with individuals living with HIV, this participant was generally healthy before contracting HIV. Becoming infected with HIV is a milestone in the individual's health experience as he can compare between before and after being diagnosed and distinguish between the health he had before and lost after. In other words the person experiences the loss of something he had, in case of a profound change in their health or losing a tooth. If you look into a dictionary you will find two meanings to the word “loss” or “to lose”. There is a sense of disadvantage and deprivation that is the essence of loss; and there is the distress and harm, a feeling of grief that is generally associated with loss (109). A person who loses -his tooth or his oral health in general- is deprived and at a disadvantage, and could also feel grief and distress as a result of his loss. When I asked another participant how he felt when he “lost” his teeth, he searched for a word to describe what he felt. He asked me “*when someone dies you know you have a period of?*”, and he replied himself “*mourning! Mourning yeah*”.

The Challenges and Limitations Associated with Poor Oral/General Health

“*Somehow it [HIV] prevents me from doing lots of things*”.

So far we have talked about the different health-related complications that the participants endured. These health problems could in turn impose various challenges and limitations on the participants. In one way or another, most participants felt limited in their personal, social and professional lives because of HIV. These limitations could be imposed by other people, or even the person himself, or perhaps by practical matters such as their health not allowing them to do certain activities. A person who feels limited believes to be unable to do some things, and as a result could feel discouraged, frustrated, or even traumatized, “*to know something I cannot do it I feel traumatized*”.

It is not surprising that some participants felt limited in their ability to do activities because of their health problems. This was more noticeable for those who had lived with HIV for a long time. A participant, who considered himself as a physically active person that used to walk many kilometres a day and swim, found that he was struggling to walk even a few hundred metres because of his diminished health. Another one who liked to be active told me that when the weekends or holidays came he sometimes felt so exhausted –because of his health- that he preferred to stay home and rest instead. Even more importantly, some participants found that the health related challenges of living with HIV restricted their working ability. Some had less strength to do physically demanding work and, like one participant who used to do seasonal construction work, felt less confident to do physical labour. Furthermore, due to the “fragile” and unpredictable health conditions -that we discussed previously-, a person living with HIV may require flexibility in his schedule that most work places do not offer. So he may be limited in his work options and might even give up trying to find employment altogether. As a matter of fact, only three of our participants were working or studying full time. One of these three talked about the challenges of working full time hours, particularly for someone who's been living with HIV for a long time:

> *"I work full time but I work 32 hours a week and I feel that it would be difficult for me to be working 40 hours, even 32 hours sometimes is a lot. [...] I know a lot of people that- I don't know anybody actually that is working full time that's been living with HIV for a long time and works, but apart from us two I don't know anybody else, all the people that I know that have been living with HIV for 25 or 30 years, they're not working. Well I think because of what I said, they feel more fragile, and see the type of work that I do if I do feel sick or if I do feel tired you know I can rearrange my schedule or you know, like they will understand, it's a possibility. And I think other people they can't do that at work, so they just prefer to not work because for them it's easier."*

The exhaustion of having to take care of one's health as well as the perception of accelerated aging experienced by some participants, can seriously limit the hours and the energy a person needs in order to work consistently full time and to establish a career. Needless to say, other factors could be at play alongside the actual illness of HIV. Some participants attributed this difficulty in establishing or pursuing a career to internal factors such as "emotional problems". External factors such as discrimination at work could also play a part. As an example one participant revealed to me that he was forced to quit his job in his home country after his employer found out he was homosexual. Others told me that PLHIV could not enter certain professions due to their health and HIV status. Although a couple of participants hinted at the topic of discrimination at work, exploring this subject is beyond the limits of this study. In any case, PLHIV face limitations and challenges in their professional lives.

Struggling to work and to establish a career becomes relevant to dental care, because it limits the ability of PLHIV to afford the dental care and treatments that the participants felt they very much needed. Since dental care is not publicly covered in Canada, and considering the high costs of dental services, it is not surprising that most participants identified costs as a major barrier to accessing dental care. Seeing that HIV has adverse effects on oral health, the participants felt they had a higher need for care that was accessible to them, as clearly stated by these two participants:

> *"… Sometimes some places I read that people living with HIV it's a good thing that they go twice a year. So me because I don't have any insurance I go once a year"*
>
> *"And it [HIV] doesn't help for the dental care and health, so I have to check it more closer. But unfortunately I don't have the money to pay dentists as often as I should do."*

In this manner, we can see a vicious cycle where a decline in health brings about challenges, which in turn negatively influence the health of the individual even further. Let us have a look at one participant's story that portrays the complex interconnection between HIV, career, and oral health. When this person contracted HIV in his twenties, almost thirty years ago, many infected people were dying of AIDS, so HIV seemed like a death sentence to him. Thus, his attitude towards life suddenly changed and he took decisions that might have shifted the course of his life, especially when it comes to his career:

> *"So maybe I change- before I knew that there was hope, I took maybe another attitude of saying well I don't care I'm just gonna enjoy certain things, so I think career wise and different things like that I think I sort of, my life shifted maybe another way."*

At the time of the interview, this participant was still struggling with starting a career, but trying to "*go back to work eventually*". Although he was on welfare, he was not feeling "*proud*" about it and felt that being on welfare affected his "*self-esteem*". His dental care was partially covered because of welfare but he did not feel comfortable with that because in his words "*I always feel sort of you know I'm not paying for it, feeling bad about it.*" He emphasized on how the costs of dental care had really limited his access to care, making him insecure and worried about losing his teeth (anxiety over health is discussed in the next section). Being on welfare also created other barriers for him, as he believed some dentists did not like seeing patients on welfare and treated those patients differently (being treated differently is a recurrent experience for PLHIV that will be explored in the next section).

The Anxiety: Fears and Concerns over Their Health

Most participants lived with an incessant "worry" or "anxiety" over their health. As mentioned previously, there is an element of vulnerability, fragility, and uncertainty in the way they experienced health. They did not know how their health condition would evolve; if and when it would get worse. They were thus consistently monitoring their health and fearing the worse. They overthought and analysed the underlying causes of arising health issues, wondering whether or not it could be related to HIV. This quotation from a participant captures these apprehensions well:

> *"Ok. Here's a thing that happens to everybody living with HIV, even today even with all the information is, fear- of the unknown, ok? And so I will retrace my steps to the beginning and I said I would live one day at a time and then I got sick, I got sick. And I have a cold, but right away I'm thinking oh this is it it's the end, I will die now, I'm dying. So always there was that fear that oh I'm dying now, every time I caught a cold or an infection, a flue."*

Feeling that they were going through a process of deteriorating health, some participants had concerns about how to manage their health and maintain function as they grow older. One participant told me about his "*insecurities of how I'm going to manage or who's going to take care of me or where am I going to end up if I'm not as… you know my health isn't good or something*." Despite all these fears the health of all participants was rather stable thanks to HIV medications that controlled their viral load and CD4 count (9). But some of the participants worried about the efficacy and availability of the medications. Some participants, especially those who had lived with HIV for a long time, had to change their HIV medication several times throughout the years and one participant was wondering, "*if I were to have to change pills there's not many pills that I can take now*". Another participant who wished to move to a smaller city from Montreal was reluctant to do so because he was worried about the healthcare services for PLHIV and his access to medications. I already suggested that living with HIV imposes limitations on an individual and this example shows that being apprehensive of the possible health complications and barriers to care limited the options regarding various aspects of life.

Similarly, some participants feared the worse regarding their oral health. They had already experienced what it meant to lose teeth and worried about losing them all and ending up with dentures, like this participant who shared his fears with me:

> *"Every time I eat I sometimes wonder if there's something I could put in my mouth just to manage the rest of my teeth, those are thoughts that comes like that, doesn't worry me. That's a worry, it's a concern that I'm going to lose them all, or I'm going to lose many of them"*

The fear of losing teeth could create an apprehension of its unfavourable outcomes. In the following example a participant shared his partner's (also HIV positive) concerns about his personal life in case he ends up with a denture. Naturally, as shown by the quotation below, the individual's worry about losing teeth can in turn create concerns about how to manage his condition:

> *"My partner had two teeth pulled out, so that was pretty hard on him, he asked me: "you're still going to like me if I have no teeth or a denture?" and the he started to get worried because one of them is showing a little bit more and there's one missing and he doesn't know: should I get like a partial, what am I going to do?"*

As might be expected, concerns about health means that some participants felt on guard with their health at all times. An example of this phenomenon was an interaction I had with one participant: this person explained that he was struggling with a persistent and unpleasant gingivitis for a few years until a dentist suggested a very helpful treatment (he is a different participant from the one struggling with bad breath that we mentioned previously). Although in the recent years he had not experienced this problem as often as before, and at the time of the interview he did not have gingivitis, he acknowledged: "*I always carry it [the treatment] with me just in case you know*", and indeed he had the bottle in his bag at the time of the interview!

Despite having concerns, the participants tried to manage their situation in order to somehow maintain their function in the face of various dental problems. However, as discussed before, they had difficulties accessing the needed dental care, especially due to their cost, which generated substantial worry and discomfort for the participants. They were uncomfortable not being able to visit dentists as often and as regularly as they wished to, especially considering their struggle with their oral health and their vulnerability. For some, this was a larger challenge regarding their oral health compared to the actual physical pain or discomfort. Some participants, particularly those without dental insurance, were left with the fear of losing their teeth without being able to do anything to prevent it. Those on welfare felt some relief for having coverage but at the same time believed that this coverage was limited and thus still had concerns about their teeth's condition. I found this quote from one of my first interviews to be particularly rich and concise in describing this experience of many other participants:

> *"So far I don't have a big problem but at the beginning I didn't have insurance for a while and I didn't go to the dentist for two years. I didn't feel comfortable without*

> *seeing any dentists, so even there is no problem and you know there is no cleaning and or if there is something wrong getting worse and worse. Before I had two root canals, I don't want root canal and if there is something wrong it should be fixed immediately. Without any dental care at least there was a discomfort. Not a big pain because I'm not at that level yet personally."*

Attitude Change, Towards Life and Health

A subtle notion that emerged from the narratives was the influence of HIV on the participants' attitude towards health. Many participants explained how HIV changed their attitude towards health, other people, and life in general. As a healthcare practitioner I believe this finding to be consequential because attitudes influence the actions and behaviours of an individual (116) including health behaviours. Whether directly or indirectly, for positive or negative, living with HIV changes a person's attitudes at one point, which in turn alters his oral health behaviours and influences his general and oral health. Several participants discussed how a change in their attitudes had affected the way they took care of their health.

The participants had mixed attitudes towards health at different stages of their lives. Some underwent a period of time in which they started to have a negative general attitude and stopped taking care of themselves, leading to degradation of their health. Previously I wrote about a participant who felt less confident and able to do physical labour due to his worsening health condition because of HIV and the medications. Not being as physically able and active as before, he started to get "*into a negative attitude*", lost his "*desire of self-preservation*", and stopped taking his medications; consequently his health went downhill to the point that he had to be hospitalized. Additionally, a negative attitude can stop the individual from trying to seek health care and dental services. One participant mentioned that besides the issue of costs, *"the influences that made me not go to the dentist were more like depression, apathy*". In the accounts of another participant, who expressed rather significant dissatisfaction with the appearance of his teeth, this subtle connection between HIV and attitude towards dental health and seeking dental care is made more evidently:

> "*And I think if I can relate it to HIV I would say that also when I was in my twenties, and at the time I thought I would die you know, because people died at the time,*

> *so all the investments that I could have done to put money aside for later, or to invest in my mouth for example like I could have decided to have some braces, so all that I decided not to do because I thought I was going to die you know, so I said why spend that money on this.*"

Nevertheless, most participants had a more optimistic attitude towards health. As mentioned before, they were constantly struggling with their health and tried to manage despite their diminishing health. It is not unexpected then that the participants were considering ways to improve their health and they had adopted positive health habits after being diagnosed with HIV. For example one participant stated that living with HIV "woke him up" and made him realize he had to "take better care of himself" and his health. Many participants brushed several times a day (more frequently than I brush!) and flossed regularly, a habit that some of them did not have in the past.

In general the participants were quick to assume responsibility over their health and tried to be actively involved in their health care. In other words their general approach was to manage and maintain their health and to "*do whatever [they] need to do to take care of [their] health*". This means that knowledge about their condition and how to take care of their health was particularly important to them. As a few participants mentioned -and I noticed for myself when I partook in one of their weekly meetings at ACCM- they exchanged their knowledge and experiences regarding their health and health care. It was important for them to feel able to manage their health. One participant contrasted HIV with an incurable cancer saying, "*I could have had cancer and not being diagnosed with a cancer and three months that I have to live and that's it*"; he thus concluded that although he was enduring a lot because of his health it was fine as it was "*manageable*".

Because of various barriers to dental care -especially costs- that prevented the participants to seek dental care and regular check ups, the participants' habit to constantly monitor and actively manage their oral health became crucial. That being the case they either tried to manage their oral health to maintain their teeth or otherwise felt that there was not much they could do but to accept the situation:

> "*Well, I at least have limited access to certain things so I feel lucky about that but just you have to get ready that maybe you're going to lose your teeth and there's not much to do.*"

Finally a noteworthy theme that I commonly noticed in the narratives of the participants was their holistic outlook on health and life in general. They talked about their health in connection with different aspects of their lives and in a general context, and rarely as an isolated theme. Time and time again I was told about their oral health is a part of their general health and even when I specifically asked them about their oral health they would discuss all aspects of their health, including general and mental health. Similarly they had a holistic approach towards healthcare. For instance, one mentioned that he liked oral health services to be offered at the same place, another said how he enjoyed his experience receiving treatments the only time his dental team and his medical team collaborated together. Although dental care is separated from other healthcare sectors in the Canadian healthcare system, the participants mentioned in one way or another that they needed connection between oral health care and general health care as they felt that it was all part of one unit.

> "*I find it too bad that it is different, it should be the same. I mean there must be a reason why they are different but they should be the same with the dentists, I mean the teeth are as important as whatever, your fingernails or even more, as important as skin.*"

Aiming to understand the experience of accessing dental care for PLHIV, we have so far explored one part of this experience, which is regarding their general and their oral health in particular. In relation to health, the participants experienced a constant struggle with hardships and obstacles. They struggled with a far from perfect oral health that they tried to maintain in order to prevent further "loss". Meanwhile their ability to seek oral health was more limited due to HIV, whether because they encountered barriers such as costs (especially since finding a job and working full time is more challenging for a person living with HIV), or whether because they felt more limited in their choice of dentists (this will be further discussed in the next sections). In other words while maintaining a good oral health and accessing dental care is a challenge for many people, PLHIV experienced an additional layer of difficulty to what is an already challenging experience. Next we will look at the participants' lived experience of their relationships and interactions with others to understand how they interact with the dental staff.

Patient-Dentist Relationship

In their social context, the participants generally experienced living with HIV as a sense of "otherness" in their interactions with other people. This means that the individual is perceived as inherently different or unusual, as "other", by people or even by the person himself. In the following sections we will first look at how living with HIV could affect the individual in relation with others, in his perceptions of himself and his attitude towards others. We will see that the individual could internalize this notion of "otherness" or being different, experiencing shame about his condition and to a lesser extent, an exaggerated sense of responsibility towards others and protecting them. Next we will explore how HIV affects others in relation to the individual living with HIV. HIV overshadows the individual's identity in the eyes of others, who may perceive and treat PLHIV differently than those who do not have HIV. Consequently the individual develops an apprehension of being treated differently. Experiencing this anxiety and the sense of otherness associated with HIV, the person living with HIV faces yet another apprehension about who finds out about his status. We will explore these under the subtheme "anticipating negative behaviours" and lastly we will look into the strategies participants adapted to cope with this anticipation.

HIV and Self: a Changing Sense of Self

The data suggests a connection between living with HIV and the way the participants perceived themselves. One after another, the participants revealed how living with HIV had positively affected them as individuals. The majority told me that HIV was somehow a positive change that improved their lives, woke them up, and made them stronger (all these expressions are borrowed from the participants). One person even light-heartedly played with words: "*there are some positive effects because now I'm a positive person, not HIV positive, positive, more positive person*". At first, this seemingly paradoxical combination of "positive" and "HIV positive", or the reported positive impacts of HIV on the participants came off as a surprising finding. But after reviewing the texts over and over, I realized that the essential meaning behind these perceived positive changes is a perceived "change in self": living with HIV introduces a "*sudden change*" in a person's sense of self and his self-image, and induces a shift in his attitudes towards life as well as other people.

We have already discussed this general shift in the attitudes of the participants in connection with their health. But as some participants revealed in the interviews, living with HIV could similarly change the person's attitude towards others as well. Their attitudes towards people and the way people behaved towards them changed in the courses of their lives with HIV; they told me how at some point they were more negative and interpreted people's actions in a negative light or how at some point they became indifferent or more positive. A couple of participants viewed themselves as having become more positive, open, and accepting towards other people, while some wondered whether they perceived the actions of others in a more negative or suspecting light at some point in their lives. The following quote from a participant who had been living with HIV for a long time, describes his views on the general attitude of people towards him and PLHIV throughout the years. Although he found that people had become more accepting, he wondered if it was his attitude towards people that had changed, making him see matters differently:

> "*I think so yeah, let's say maybe my attitude towards people's attitudes. Maybe I would see things before that actually were true I don't know, but seems to me that people are much more relaxed about it than they used to be… Or maybe it's just that I don't see those things anymore. Or maybe it was part of a paranoia that I would see more, maybe before, it's hard to say how you were before, maybe that paranoia has been fading. Or maybe it's jut that people are more accepting, I haven't really had much discrimination.*"

Whether it's for positive or for negative, living with HIV changes a person's sense of self and his attitudes at one point, in turn influencing the way he perceives the behaviours of others towards himself. The link between HIV and a sense of self or identity is quite essential to understand what it means to live with HIV. When I asked a participant to tell what it meant to live with HIV, he talked about his facial lipoatrophy, which is the loss of facial fat tissues and a flattening of the face as a result of highly active antiretroviral therapy (HAART) (117):

> "*… some people tell me oh it doesn't look that much [his lipoatrophy], myself I know because I know what I looked like before, my face was a lot full and round, and so I know like when I see myself in the mirror I see somebody living with HIV for sure.*"

This quotation makes it clear that the participant's concern about his looks was not just about how others perceived him (although that was also a concern of his and it is later discussed in this chapter). Although his case of lipoatrophy was not severe and remained unnoticed by most other people, he noticed it when he looked in the mirror. He knew how he looked before and he was the one who perceived a "*change*" in his face. It was not only about the image others saw of him; rather it was about him and the image he perceived of himself. He wished to look -what he considered as- healthy, but what he saw of himself was the image of someone living with HIV.

To further understand how HIV could affect an individual's sense of self, I will describe a pattern I noticed in the anecdotes of some participants. Although it was beyond the scope of this study to ask participants about how they were infected –and our co-researchers advised us that this could be a highly sensitive subject for a person living with HIV- some touched briefly upon the subject in their narratives. For example, one participant referred to it as "*that one mistake I cannot take back*". Similarly other participants explained: "*it was my fault, and I will do whatever I need to do, and I took care of my health and so far I'm ok*"; "*I know the type of life I did live, and well I made my choices and there were not for sure very appropriate for a healthy life.*" However, not all participants shared the same feelings. For example a participant clearly stated "*I never had really a problem with HIV between me and myself. I didn't feel guilty or it's my fault, I assume my responsibility.*" In any case, these statements imply a sense of guilt associated with HIV on the part of some participants. They perceived a "mistake", a "fault", a series of "bad choices" on their behalf indicating that they should "assume responsibility" for their condition and managing it. Although this is a pattern in the narratives, the following quote from one participant conveys both the bad feelings some individuals carry for having HIV as well as how they were affected by these feelings. He was explaining to me why he did not change his dentist despite finding the dentist's behavior somewhat discriminatory:

> "*Sometimes when you're in this situation I think as an HIV positive person you're also very- you kind of feel bad, having this virus, and it's a virus that can be- that is communicable, so you're kind of feel you don't really know you know, you don't- you trust these doctors but then you don't really argue with them because you think ok maybe they- you feel lucky you know that somebody's wanting to treat you and then you just don't want to create too much of a fuss there*."

To "feel bad" or to have feelings of guilt or shame could affect the way the individual perceives and experiences his interactions, as well as his demands and expectations with others. I was having a conversation with the same participant about the stories he had heard from other

PLHIV related to their good experiences with a young dentist, who apparently received all patients regardless of their HIV status, sexual orientation, or being on welfare. As he was telling how hearing these positive stories have affected him, he began to reflect on himself and his expectations from his current dentist. He started to realize that he was used to having lowered expectations from dentists because he felt bad about having HIV; he felt "lucky" just to have been accepted by a dentist, which means that he expected to be rejected, and that his satisfaction, or lack of dissatisfaction with the services was partly due to his lowered expectations and demands. While talking to me, he realized that he had the right to have the same demands as anyone else because he was "*as good as anybody else*".

> "*The impact that it had on me is that why am I thinking, you know, that I'm so lucky to have my dentist because he's willing to see when there are some dentists that really don't care you know. So I've been having a kind of a change in my relationship, not thinking I should be so lucky to have this dentist, because that's been a bit my attitude to no to be too demanding and well now I'm thinking maybe I could be more demanding because I'm not- I'm as good as anybody else, my money is as good as anybody else you know.*"

HIV and Others

HIV Overshadows the Individual

Previously we mentioned that HIV could influence PLHIV's sense of self. Similarly, having HIV could affect their identity in the eyes of the others, which can potentially be in contrast to how they perceive themselves. To them HIV is a personal matter, a "*part of my personal life*" and not a part of their role or their image within the society: HIV is "*just a virus in my body*" or "*just a part of your life, that's it, just a part of your life*"; yet in interaction with others it becomes a part, if not the highlight, of who they are. They want to be known with their professions, or characteristics that they think define them in the society, but they worry that when others learn about their HIV, they will be the "*AIDS guy, and the other parts will be disappeared*". Hence, HIV and other traits associated with HIV could overshadow the social identity of people living with HIV, leaving them to wish "*to be known as a person, who I am*" instead of someone who has HIV.

Furthermore, depending on the location and social context, HIV may be associated with different labels, certain behaviours or specific groups of people. Firstly HIV is a chronic illness that is considered as a disability in some parts of the world, including Canada (118). Nevertheless, the individual may not *"want to be considered as a sick person or disabled, handicapped"* because that is not who he feels he is. In the experience of the participants, HIV was most prominently associated with homosexuality in Montreal; even the heterosexual participants mentioned that some people assumed they were homosexual because they had HIV. On the contrary a participant who had lived in another Canadian city for a few years experienced HIV was associated with poverty and the aboriginal community there. So PLHIV may feel that they are perceived through the lens of certain stereotypes associated with HIV and treated accordingly.

Moreover, HIV is different to many other chronic or debilitating conditions in that HIV could be transmitted through sex or drugs, thus associated with certain lifestyle or behaviours. Therefore, especially in conservative communities as some ethnic immigrant or religious circles, the participants found that sometimes others "*immediately look at you differently*" and "*discriminate HIV positive people*". This type of experience is not limited to conservative communities. Many participants shared with me that, even within the homosexual communities, they felt "discrimination" or "prejudice" towards PLHIV. "Prejudice" is defined in the dictionary as "preconceived opinion that is not based on reason or actual experience" (109). So the participants felt that others tended to make false assumptions about PLHIV merely based on their HIV status. In this sense HIV becomes more than just an illness in the prejudice that is attached to it. This could be particularly challenging for those already belonging to a minority group, such as the homosexual community, and make them feel like minorities in their own community: a "*minority in minority*".

> *"You know even in the let's say gay community you would think it's something that was part of, it affected a lot of people but even there I mean some people don't like you as much if you reveal your status and it's not just when you want physical or sexual encounter or whatever, it's just- yeah some people are uncomfortable, they might be uncomfortable about it because they're scared that they might have it, who knows. But I see that it's around and I can't say that it's affected me directly but yeah I see that there is still even years later it is, yeah there is still prejudice from some people. They don't*

> *understand- it's not an illness- sometimes I felt like for some people it wasn't the same illness as others because it's usually transmitted by drug use or by sex, those are bad things so sometimes prejudice because of that."*

Needless to say, PLHIV could undergo a similar experience in their interactions within healthcare settings. However in addition to their identities, a couple of participants felt that their health was overshadowed by the fact that they had HIV. As discussed earlier, HIV is a crucial factor in the health of a person living with HIV; nevertheless HIV is only a fragment of the individual's total health concerns and it is not the whole picture. The dentists or any other healthcare practitioner may fail to see the patient living with HIV and his health issues beyond HIV, leaving the person feeling that:

> *"You know sometimes they think everything's going to be HIV, so they will see you primarily as someone living with HIV and maybe you can have other health problems."*

Others Act Differently Because of HIV

HIV overshadowing the identity of the person means that in the eyes of other people HIV is associated with who the individual is as a person, in other words his identity. It is for this reason that I chose the term "to other" to describe this essential aspect of the participants' experience of their social interactions. To other someone is defined in the dictionary as "to view or treat a person or group of people as intrinsically different from oneself" (109). When HIV defines the individual, he is viewed as intrinsically different compared with others who do not have HIV; the person with HIV is viewed as different, as "other". Such a perspective would naturally manifest itself in the actions and behaviours of those who hold it towards PLHIV. According to the participants these behaviours range from subtle signs of being uncomfortable around the PLHIV, to a sudden change in attitude upon learning about the HIV status of the person, treating PLHIV differently compared with others, or even rejecting them (as their family or community member, or the healthcare provider). Our data suggests that PLHIV are sensitive to these indicative signs in the behaviours of other people towards them.

In the paragraphs to follow, we will describe the participants' experiences of "otherness", with a focus on healthcare settings and the dental staff in particular. It is important to keep in mind that what the participants experienced on a daily basis in various social contexts affects their interactions with healthcare professionals (and vice versa). Thus it is important for the healthcare practitioners to understand that each patient living with HIV comes with a history, a set of experiences that have shaped his interpretations and worldview, and we cannot isolate the healthcare settings from the society. Additionally it was not inky the first hand and recent experiences of unfavourable behaviours from a dentists or other professionals that affected the participants. Many of the examples our participants shared with me were past experiences or stories they had heard –directly or indirectly- from other PLHIV. Interestingly, most participants did not remember facing negative reactions from dental staff themselves. But as we mentioned earlier, health and health care were significant matters for our participants and other PLHIV, and for this reason they commonly exchanged their experiences with each other. In this way they hear stories from one another that played a key role in how they assessed dentists:

> "*Well some dentists, and this not my personal experience but something that I heard from others that dentist were uncomfortable with people living with HIV and had the tendency to maybe suggest them to see another dentist? If they are keeping these clients it would be more difficult to get an appointment at the time you're vulnerable, it's less easy when the professional whatever the profession is, is not comfortable with HIV, it would be different.*"

Back to the participants' experiences with being "othered", they sometimes perceived even subtle changes in someone's behaviour as an indicator of that person treating them differently compared to others. A behaviour that the participants most commonly noticed was when the other person was not comfortable around them. Being uncomfortable indicates that the person is uneasy with the situation and not in his normal state of being, and therefore treating the individual differently than one would in a normal situation. A participant told me that:

> *"As soon as I'm detecting discomfort I'm going to ask the question why you're feeling differently or your reaction is different"*

Thus, when someone was uncomfortable around him, the participant interpreted it is as a sign that this person was "feeling differently" and perhaps "reacting differently" because of the participant's HIV. This quotation also shows that signs of "discomfort" could be "detected" by the participant. When I asked him how he "detected discomfort", he described his encounter with a healthcare professional who "*was completely not aware of HIV. He didn't know how to react* *and the discomfort that he was feeling about it made him react weirdly toward [him]*". In this situation reacting "weirdly" and not knowing how to behave were detectable signs of discomfort that the participant interpreted as the professional's lack of awareness about HIV. Many participants interpreted this lack of awareness and knowledge, especially from healthcare providers, as a form of discriminatory treatment or as an underlying cause of discrimination. Yet most participants believed that it was mainly "fear" or stress that made people uncomfortable around HIV, and hence they recognized signs of fear such as breathing fast or sweating as indicators of discomfort with HIV. One participant described the attitudes of most dentists towards him as discriminatory and rooted in fear. When asked about examples of such discriminatory behaviours, he responded "*how about exasperation?*", and then he let out an audible forceful breath: "*when you hear that from a human being it means there is a lot of stress on them*".

> *"So when you start showing signs of fatigue, or stress, because it shows in many ways, in the way you breathe, in your posture, in your body language. You can see when people are nervous, even in their eyes. Yes so basically I could just sense it without any words spoken."*

This participant believed that by showing signs of distress or discomfort, the dentist expressed his unease treating him due to fear and prejudice of HIV; this behaviour signified that the dentist considered him differently from the other patients. It is no surprise that when I invited the participants to imagine an ideal or good dentist, they often replied: someone who "doesn't care" about HIV. A dentist who "does not care" does not hold any fear of HIV or prejudice against PLHIV in his innermost beliefs. Even though showing subtle signs of distress or discomfort was not necessarily interpreted as an act of discrimination, it still conveyed the impression of hidden fears or biased beliefs that could lead to discrimination. What the participants regarded as discriminatory behaviour however, was a sudden change in the behaviour of the professional when they disclosed their HIV status:

> *"What I don't like is the change of behaviours from a professional whatever the professional is, when he knows that you are HIV positive that suddenly his behaviours will change. So he will be more distant, he won't shake your hand, he will be less friendly. Well if you were used to visit or to see the same professional and you were coming in his office shaking hands and suddenly right after you disclose your HIV status*

> *he doesn't shake your hand anymore, before disclosing he never used gloves now he's using gloves, some difference in his behaviour and when I detect this I'm asking always the questions why it's different this time than before I told you I was HIV positive, are you feeling uncomfortable with this, do you want to talk about this."*

Once more we can read from this quotation that even subtle changes in someone's behaviour could be detected by PLHIV. Even when the participants could not put their finger on it, they could "feel", "sense", or "interpret" a change in behaviour. As one participant expressed *"you cannot define this, you can only feel it";* another mentioned *"I cannot prove he discriminated me because of my HIV, but his attitude changed"*. They could sense a change in the body language, the smile, or as they most commonly referred to, in the tone of voice of the other; they wondered about the reason of such changes and concluded that it had to do with their diagnosis of HIV.

> *"So basically body language speaks louder than words. And so I had experiences with dentists that I did not divulge my HIV status, and they always seem to be- there's a certain body language and pleasantry that is you know happening each moment that I'm in the chair or leaving them or coming into the dentist's clinic, being treated and [they say in a cheery voice] 'oh ok, oh great, X we'll see you in six months, great!! Your teeth are awesome.' [I say]: 'Thank you doctor X and we'll see you in six months unless I have a cavity or a problem before that, but we wish not. And so [with a cheery voice] all right! Have a great day! Blah blah blah.' But you see that changes as soon as you put on the thing HIV and you give your earlier problems that you use the medications, and then they- I see it, I feel it, I can interpret."*

The participants shared several stories of such incidents with healthcare professionals, and compared their experiences with healthcare providers who knew their status and those who did not. One participant made the conclusion that his only good experiences with dentists were when they did not know about his status. He shared a story in which he decided to disclose his status to a dentist. Before visiting this professional, he had been treated in a satisfactory way by a dentist who was unaware of his status. Then he moved to Montreal and decided to disclose his status to his new dentist. But as he narrated "*I realized each time he did a job it was not good. He did a job on me just cleaning, and it took less than 20 minutes, I said wow I'm in and out of his* *chair in less than 20 minutes.*" The participant observed that the dentist rushed the procedure and he felt a change in the quality of care he received because of his HIV.

Sometimes the participants perceived these changes in behaviour and quality of care as "rejection". Quite a few mentioned that since it was illegal to reject clients because of HIV, some professionals tried to discourage them from consulting by making their access difficult or unpleasant. For example a participant talked about his experience with a surgeon that treated him twice: the first time the participant did not declare his status and all went well; the second time, as he had started HIV medication, he declared his medication on the health forms he completed before the surgery. He realized that on the day of the surgery, unlike the previous time the surgeon did not check on him as he was waiting in the hospital room, and his operation was constantly postponed for reasons that he found unjustified. Finally he decided to cancel the operation himself and left the hospital, as he told me "*I got the message*"; the message being that the surgeon did not wish to operate on him. At the time of the interview, he still had the same health problem because he stopped seeking a treatment after what he went through:

> *"Before HIV he treated me a certain way, the same doctor the same hospital same department, almost the same problem, and until he knows I'm HIV he was the same person acting the same way. After I filled out the form, the reactions were different. You can sense this reaction. You cannot measure… So you feel, I feel, there is something different now. And the only difference before or after is HIV, this is why I made the connection."*

What distressed participants the most was not necessarily being denied the same quality of professional care. The participants associated certain behaviours with the general demeanour of dentists, showing that they held preconceived notions about how dentists usually behave with patients: dentists tend to smile and exchange pleasantries as well as friendly conversations. They were mostly troubled when they observed that they were treated differently compared with the other patients when it comes to the humanistic aspect of the relationship. In addition to the same quality of services, the participants expected the same quality of behaviour; as one aptly put it: all patients expect "*the same quality of smile*".

The participants placed great emphasis on the importance of being treated no differently than any other patient; so much so that they believed a good or ideal dentist is above all someone who treats them "*just like everyone else*", "*the same as any person*". This argument was brought up time and time again in multiple interviews. Nevertheless the participants considered it acceptable, in fact favourable, that the healthcare professionals took the specific health needs and conditions of patients living with HIV into consideration. Of course, they expected the professionals to take HIV and the differences between individuals into account only to provide better care to each individual and not for discriminating. I found this quotation from one of the participants quite well articulated on this regard:

> *"Professional-wise or healthcare-wise you might be different but as a person, they should treat you the same as any person, someone in the street homeless, or you come here with BMW, nice person or very healthy person, same treat as a person. But health-wise, healthcare-wise that's a dilemma, healthcare-wise everybody has a different situation, they should consider these different situations to heal your problem to solve your problems, not to discriminate you, not to differentiate you."*

Nevertheless, all participants either had experienced or heard stories that dentists unjustifiably treated PLHIV differently. Such instances ranged from a dentist -or other healthcare professionals- using extra protective measures (like using double gloves or plastic covers or a different dentist tool kit for PLHIV), to a dentist asking the patient to come a specific day of the week or as the last patient of the day, or to a dentist claiming that he was not knowledgeable about HIV so the patient needed to visit another dental clinic or go to a hospital. The following narrative was among the most drastic participant's account of such behaviours. To the participant this experience "*was so extreme it was so dramatic that it was kind of funny in a way*":

> *"He's a very nice man, but obviously didn't have current information- I don't know I'm not sure there's a lot of hypothesis as to why he was doing the way- the things the way he was doing then, but I would go to his place and he would put plastic everywhere, on everything, not on the reception but in the actual dentist's where he do things you know, so everything was covered in plastic. And also the hygienist would not be the one cleaning my mouth. She was there, but she would be doing something else, so I don't know if she didn't want to do it or he felt like he needed to protect her."*

All participants stated that they understood the need for the dentists to protect themselves, their staff and all their patients. I suggested in a previous section that there is a sense of responsibility associated with HIV and in fact all participants were concerned about protecting others and wanted the healthcare staff to take all the necessary protective measures. Yet again, they felt uncomfortable when healthcare professionals used different precautions for treating them compared with the other patients, like this participant:

> *"When you give blood sample, they have to put gloves but you see there's another patient they don't put gloves and then you're sitting next and when it comes to you they definitely put… I WANT them to put gloves, just in case, but put them on with the other patient as well, at least I could feel comfortable."*

As we discussed in the previous section on attitudes towards health, the participants were considerably involved in their health and the above comments further demonstrate that they gathered updated knowledge and information. Therefore if they were to be treated in a non-standard way, they expected this to be scientifically justifiable and explained to them. Most participants shared with me the information that many people who live with HIV in Canada are unaware of their status and therefore their condition is not controlled. They added that these people are more likely to transmit HIV to others compared with the participants who are on medication and have an undetectable viral load. Many participants also knew and talked about universal precautions, which means treating everyone in a similar way as if everyone was potentially HIV positive. Taking all these facts into account, they wondered whether the healthcare professionals were justified in using different precautions for PLHIV. The participants did not find the above-mentioned behaviours such as using -the notorious- double gloves justifiable and thus associated them with discrimination, rejection, a lack of willingness to treat PLHIV, or at the very least a lack of sensitivity or knowledge about HIV and PLHIV on the dentist's part.

Although none of the participants had been openly refused by a dentist or another healthcare provider (it is illegal after all!), they interpreted certain behaviours – as we saw earlier - making access difficult for PLHIV as a form of legal and polite rejection. It's important to put this in a larger context: almost all of them had experienced rejection from their workplaces, communities, or even their friends and families, because of having HIV. A few participants shared with me that they had not spoken to members of their families for a long time. Another told that in his community "*if you are HIV positive, you are out of the community*". Surprisingly, many participants believed that discrimination against PLHIV was prevalent in the gay community. They did not expect this because they had been rejected for being homosexual and thought they had finally found acceptance within the gay community, which they considered as a second family. As one participant expressed when sharing his feelings on discrimination against HIV in the gay community, to feel rejected is an experience they "did not need in their lives again". They perceived this lack of acceptance by someone from whom they expected support and understanding, such as a parent or a member of the community, as a painful form of rejection.

> *"Well yeah it's disappointing, I mean you feel some anger, well you feel rejected. And when you're gay you've been rejected a lot because of that, and you think that you've found your family in the gay community and you won't be discriminated against and then you are because of HIV. You feel that you don't need this experience in your life again, so it hurts because it's the people that you thought were your family and should understand."*

The same feeling could apply to healthcare professionals, from whom the participants expected care regardless of their HIV status: being rejected was a hurtful experience that left them frustrated and isolated. The initial reaction of some participants to such behaviour was to feel angry and annoyed. Furthermore they sensed a dehumanizing aspect to certain behaviours, in particular in the tone of voice some people used for addressing them. A participant reported the "*dehumanizing*" "*disdain*" in the tone of voice of a family member who spoke to him as if he was worthless, while another said that he sometimes felt like "*a second class citizen*" in his interactions. A person who feels dehumanized feels that he is deprived of his positive human qualities (109). Instead the participants wished to be treated with "*compassion*", "*empathy*" and in a "*humanistic way*" similar to everyone else.

The most significant effect of discrimination was losing trust in the dentist, and generalizing this distrust to dentists and healthcare providers. When I asked a participant how he was affected when his surgeon suddenly changed his attitude after learning he was HIV positive, he quickly responded that he learned "*not to trust even doctors"*. Another told me that although he liked his dentist, there was "a little distrust" because he used to have a different dental toolkit for him. A third participant said that "*[he] didn't trust [his dentist] too much*" because "*his cleanings were way too fast*", and extended his distrust to all dentists:

> "*[This experience] affected me… Basically I trust them even less now. How did it affect me? I have no trust for dentists. I am yet to find a good dentist, I have yet to find a good dentist.*"

Many participants stopped visiting the healthcare professionals that they believed had treated them in a discriminatory manner. Conversely, they gave their trust to the dentists who did not treat them differently and were not uncomfortable with them. A participant shared his feelings towards his dentist by telling me: "*I trust him, I trust the dentist, he never asked me to come late in the day*".

On occasions the effect of discrimination on some participants was to lower their demands and expectations. This was especially evident in the narratives of one participant who had been living with HIV for a long time. Several years before he visited a dentist who asked him to come on a specific day of the week; feeling annoyed by this request, he decided to never return to this dentist. His new dentist accepted to receive him as the last patient of the day and because of his past negative experience, he was happy with this arrangement. Later this would change and he didn't have to visit the dentist as the last patient of the day any more. However, the dentist used a different dental tool kit for him to which he did not object since this was an improvement on the previous conditions. In addition to accepting discriminatory behaviours, it was also possible for the participants subjected to discrimination to start questioning themselves and their interpretations, wondering if they were being "paranoid". The participants also suggested that it was possible that their attitudes became negative after negative experiences with healthcare professionals, as this participant explained to me:

> "*Well yeah, if I have good experience I will keep going, if I have bad experience you will think about it twice what I'm gonna do. Because you eliminate one choice, and a second choice because you are coming with a bad experience to the second choice the other choice, even your attitude will be harsh and you will not be the same person. Before bad experience you go it's ok it's good and then second, now your attitude becomes negative as well. And it's a kind of avalanche effect.*"

After going through negative encounters with others, the participants became apprehensive of living the same experiences again. This apprehension is key in understanding the approach of the participants towards healthcare, as we will explore next.

Anticipating Negative Reactions

> *"It was last year. Well usually I just go there, and sometimes a little late, and they're cool with that mostly. And I mean they're super nice. They're as I said you know*

> *my hygienist that I had her for a long long time- also when I first had her she was not wearing glasses like you know now they have these glasses, so after a while they start wearing glasses and then you're thinking: 'are they wearing these glasses just with me or do they do this with everybody now?' and I'm not sure I'm not sure. I know now they do it all the time with me, the glasses, and I know the procedures kind of changed over time, I guess now you know. I go there and she cleans and she has her glasses and stuff like that, it goes well, sometimes I freak out a little bit when there's blood you know, not because I think it's dangerous, more I'm thinking: 'oh god she's going to freak out,' but she doesn't."*

This is how a participant replied when I asked him to describe his last visit to a dentist. He told me that he was generally satisfied with his dentist of many years and described his visits as "uneventful". And indeed in this account of the events, the hygienist was taking standard precautions (I had to reassure him that it is common practice to wear protective eyewear with all patients) and in the end she did not "freak out" after all. Still, while on the chair, he was observing the behaviour of the hygienist, wondering if her actions were related to his HIV status ("*is she wearing glasses because of me*?"), questioning if he was treated differently from the others ("*do they do this with everybody now*"), and anticipated a negative reaction ("*is she going to freak out because of the blood?*"). In this example, the participant was not experiencing discrimination, but anticipation of discrimination, or what I am going to refer to as anxiety. Anxiety is the apprehension, the uncomfortable tension and anticipation of something unpleasant (109).

We have already explored the health-related anxiety of the participants. When it comes to their interaction with others, discriminatory behaviours not only made them feel uncomfortable, it also created an apprehension of going through the same experiences and feelings again. Having had negative experiences in other contexts, especially in other health care settings, and hearing stories of PLHIV being discriminated at the dentist's in particular similarly affected the participants. The participants worried that others might judge them, treat them differently, or even reject them after learning about their HIV status. In addition to the anxiety over how others would react to them, the participants were apprehensive about who may find out about their status. We will discuss this in more detail next when exploring the issue of confidentiality.

While experiencing discrimination could affect the individual's attitudes and perceptions, apprehension of discrimination can influence the way the individual acts, as we will see later. In fact the anxiety of discrimination could transcend actual discrimination for some participants:

> "*But if I go back to discrimination, experience of discrimination, I mean a lot of these things you're just afraid that you're going to encounter.*"

Confidentiality

Previously we looked into the narrative of a participant who reported a mild case of facial lipoatrophy (the loss of facial fat tissue associated with HAART) and the impact it had on him and his self-image. He added that many people in the gay community knew how a person who had been living with HIV looked like, so whenever he went to the "gay village" in Montreal he felt that others could see it in his face: "*they look at me and they double look at me*" and then *"I see in their eyes that they know"*. According to him, many people living with HIV for a long time had experienced this feeling, contrarily to those more recently infected, who did not have facial lipoatrophy and could "*remain anonymous*". By sharing this remark he revealed a concern of whether or not others knew about his HIV and a desire to keep his status confidential.

All participants, including those who were open about their status, were unanimous that they needed to be careful about who knew of their HIV status. Their need for confidentiality was partly due to the fear of being discriminated against or the apprehension that people may change their attitudes towards them. Yet in many cases the participants did not necessarily anticipate a negative reaction, they were rather concerned that everyone in their community or circle would know of their status. They worried that "*the wrong person*" would find out and "*spill the beans*", making the situation as well as the information out of control, it would be "*like the cat is out of the bag*" in the words of a participants. If their fears did come true and someone in their circle intentionally or inadvertently breached their confidentiality, they could feel betrayed and furious:

> "*Sometimes you just tell the wrong person, and then they tell- either you tell a blabbermouth, or you tell a wrong person that tells a blabbermouth, and that was my situation. So basically it got to a point where everybody knew [...] when it comes to secrets and that, if you want to keep a secret just don't tell anybody.*"

Confidentiality was a particularly major concern to one participant belonging to an immigrant community. He told me that he would never tell anyone in his community because in his opinion "*if I tell only one person everybody will know, in a day*". His apprehension made him feel "*a little scared*" and "*traumatized*" to the point that he avoided individuals not only from his original country, but also people from many other immigrant communities in the ACCM community, fearing that they would tell someone he knew about his HIV. He "*felt so uncomfortable*" when he encountered someone from his country participating in activities and meetings of PLHIV thinking "*oh no he's gonna tell everybody the news*", that he stopped attending meetings where he could encounter this person. This reveals the isolating impact of his fears.

Confidentiality is one of the ethical and professional responsibilities of anyone providing healthcare. Considering the concern of PHLIV on this issue, confidentiality becomes a crucial and sensitive matter. In spite of this some participants experienced instances in which confidentiality was not respected or their information was not handled correctly. One participant remembered an incident where the staff at a hospital asked for specific information on his files and instead received the complete dossier, including information on his serologic status. This breach in confidentiality made him worry that information might be accidentally released and that everyone would learn about his status. Even participants who were open about their HIV status held concerns about confidentiality at the dentist's office. The next quotation is from such a participant. First he thought that confidentiality was broken when he saw that his file, with his name and his HIV status, was open and visible on the receptionist's desk. When he decided to protest, the dentist invalidated his emotions and did not show sensitivity to his concerns. He never returned to that dentist and later added the dentist' name on the blacklist of health professionals at COCQ-SIDA (we will discuss this list in the next section). Respecting the confidentiality of PLHIV is an evidence of understanding and compassion for their specific needs and experiences and failing to do so can lead to losing their trust.

> *"For most of the time I had good experience in dentist's office, except one that at the reception, my file was on the counter and it was written HIV, that was visible when you were on the counter. So there were my name and HIV. Yeah it was frustrating, and not acceptable so I ask the receptionist to turn the file and never do that again. And the dentist was coming at the same time and it seems like he was kind of agreeing with his*

> *receptionist. Well he mocked, he was like this is not important. So I said: 'no that is important this is confidentiality break when you are exposing a file that is visible to other patients coming to the desk and you have your name and HIV on the files.'"*

The letters "HIV" on a file are not the only things that could give away the status of patients living with HIV. Asking the PLHIV to consult on a specific date or time means that anyone who sees them coming at those times can guess that they are HIV positive. One participant told me that when they specified a certain day to treating PLHIV at a CLSC (local community service centre) he could see that "*some people come at the last minute and immediately they leave*" because "*they may have a feeling oh I might be known, I might be seen here*". In the late 80s when one of the participants, recently diagnosed with HIV, decided to disclose his status to his dentist, he was asked to come on Fridays. Annoyed by this request, he decided to find another dentist, *"I was thinking that that means that everybody that sees me going to the dentist that day potentially they know that I'm HIV positive, because that's the day for HIV positive so I didn't like that at all"*. Similarly, several participants felt discomfort when the hospital staff they were consulting talked loudly about their status, allowing other people around to hear.

I found it particularly interesting that it's not only the healthcare staff, but also the healthcare "space" that should respect patients' need for confidentiality. Two of the participants' main complaint about their dentist was that they felt "*strange*" and "*uncomfortable*" because of the open space design of their offices. They could occasionally hear the other patients and concluded that it was possible for other patients to hear them as well. Thus they were "*conscious*" about what they said and the tone of voice they used. One participant felt that talking about his health was like "*walking on eggs*" and that he was "*dancing around*" when he wanted to talk about HIV, and this created a barrier to discussing his health with his dentist. Furthermore, he was "afraid" that the other patients might hear him, and he thought that because of this if he ever talked about his HIV in a regular tone of voice the dentist would feel uncomfortable as well. He drew a comparison between his visits to his doctor where "*you're never thinking oh I can't talk to them about certain things because other people will hear or because other people will think this and that*" and his experience at the dentist's:

> *So what I'm very conscious of now is that there's somebody- it's an open space you know, like often it is, and there's somebody in- like I can hear another person being*

> *treated and then if she's asking me or he's asking me something about my health I'm always afraid that the other person will hear. I'm not afraid that the person will know that I'm HIV positive, I'm just afraid they will decide I'm not going to that dentist any more you know because he has patients that are living with HIV. So I kind of don't- I kind of downplay things that would be happening with my health I don't give a lot of details because I just feel that it's not a very confidential space you know? So that's the part that I dislike now.*

Strategies

I must admit that in the beginning I was pleasantly surprised to hear that most participants had no or little experience of discrimination at a dental office. One possible explanation for this, as suggested by some participants, is that the perceptions and general attitudes of people towards HIV/AIDS and PLHIV have improved in the recent years. This could be partly due to the fact that HIV is not the death sentence it used to be (at least in Canada), thanks to the medical advancements, and is thus less feared. Besides, our participants lived in Montreal, a big cosmopolitan city where they found people to be generally open minded and relaxed about individual differences. But perhaps more importantly, as I learned after doing a few interviews, the participants adapted certain strategies to protect themselves from being exposed to discrimination. Anticipating a negative reaction from dentists, the participants had two main decisions to make: how to find a dentist they could trust, and whether or not they should disclose their status to the dentist. In the next two sections we will have a more detailed look into these strategies.

Selecting a (Trusted) Dentist

I suggested earlier that after having negative experiences with dentists or healthcare providers in general, the participants were likely to lose trust in them. One participant told me that he did not trust his last dentist because the teeth cleanings were too fast (a different participant than the other one who had the same complaint), so he decided to find another one. When I asked how he selected his new dentist this is how he responded:

> *"- I asked around, I had the dentist I had to wait for a long time I had to come back the next day at the clinic, I asked around. And I was told this doctor does a lot with HIV patients, so I went to him… But anyways it's other patients again, people that have HIV there, I spoke to them about that, because I wanted to know an HIV doctor. I mean a doctor that treats HIV patients, if you know someone who's open to that you don't have to test them, test if he's bothered by having an HIV patient.*
>
> *I: But you have never been to a dentist who you thought was bothered?*
>
> *- No to avoid this situation, I ask people with HIV, which dentist to go to."*

Although this participant had not felt discriminated against by a dentist nor could remember any such stories from other PLHIV, he still asked around in order to avoid having to "*test*" a dentist who was "*bothered by having an HIV patient*". He didn't want to encounter a dentist who would fail the "test", who according to him is someone who would "*have a dehumanizing attitude towards*" him. When I asked him if he had ever experienced someone being dehumanizing towards him, he replied that one of his family members treated him that way. This conversation shows how a person living with HIV, having experienced discrimination (not even necessarily by a dentist) becomes apprehensive of living the same experience at the dentist's and seeks to prevent it. According to our data, PLHIV commonly ask around for a "*safe*" dentist who visited many patients with HIV, and was therefore less likely to "*reject them*".

On top of that participants believed that a dentist who receives many PLHIV is experienced and knowledgeable about HIV, and less likely to be discriminating. As previously mentioned, in the opinions of many participants a lack of knowledge about HIV is a reason behind fear of HIV and prejudice against PLHIV. However, they found that most dentists were not knowledgeable enough about managing HIV positive patients and did not know how to react to them:

> *"I think they don't know much really about HIV, it should be included in the training, yeah, in the training in the school, more time more detail more information about HIV, what is really HIV, when it makes a difference and when it does not […] now it's fun to know that your dentist knows how to react or knows what is going on with you and wont panic when he knows that you are HIV positive."*

For this reason some participants preferred going to places that were more likely to receive HIV patients, such as the clinics close to the gay village, in the city centre or the general hospital. On the other hand some did not feel comfortable consulting in suburbs or smaller cities because dentists were less likely to have experience working with PLHIV.

Consequently, the ACCM developed with and for its members a list of trusted or "experienced" professionals, i.e. professionals who collaborated with the centre or were willing and prepared to accept PLHIV. Members of the community could then be referred to these professionals by the centre or choose a dentist in this list: *"you could be sure to go to and you won't feel discriminated and you know they know about it and they accept that and it's not an issue."* Those who had used the list found it very helpful. For example one participant, who had difficulties choosing a pharmacist, found one in his area with the help of the Centre and described his experience as "*so easy and she was a very experienced and took care of me*".

In addition to this list of trusted professionals, a participant informed me that there was a blacklist of dentists at COCQ-SIDA. When a participant had a negative experience at a dentist (the incident with the patient's file open on the secretary's desk, which we discussed before under "confidentiality), he could put the dentist's name on the black list and he did the same when other PLHIV told him their stories of being "politely rejected" or discriminated against by dentists. According to this participant, this list was not released but members could call to make sure that the dentist they wanted to visit was not on the list. As he put it, in this way members could protect other members from going through the same negative experience:

> *" I'm the kind- my first reaction is I'm going to take the walk to see this dentists and have a little chat with him or her, and then I'm calming down and I'm nourishing the black list dentist or professionals and ok this one if somebody is calling us to have a referral to a dentist or another professional then this one will not be on top of my list. So I think is what I can do to preserve anyone to have a bad experience with this person."*

These strategies offered a level of reassurance that balanced the apprehensions of the participants when it comes to choosing a new dentist. The downside was, however, a more limited choice or even a lack of choice in smaller cities, as this participant explained:

> "*Also in the medical establishment what I had to say is that, or the dental you know health in general, is that in a big city like Montreal you can check you know, you can do a little enquiry about where you would be received the best. You have the choice. You can check you know would I be better in an HIV clinic, or you know side clinics that are in hospital settings, so you have the choice and then you can pick the places that you*

> *feel are best for you. And then if you're not happy with a setting, you just change. And it's the same for dentists. So that kind of tainted the experience because you will, and also you know naturally you will be, even if you live in Cotes des Neiges you can decide, you could go see your regular doctor but you could also think oh maybe my regular doctor won't feel super comfortable about me being HIV so maybe I would prefer to go somewhere else. I think people will do these things, when in smaller settings they won't have- there will just be a few doctors and then people won't have the choice.*"

Disclosing

> "*But this dentist I didn't say, there was a list that questioned HIV, I didn't choose anything. Because I didn't know these people and I don't know their reaction. Before it happened to my friends and I heard some bad reactions. Because right now I'm in a small place, and if I write this who knows if the secretary sees or another person. It's confidential yes, but for another thing in the hospital, they asked my file for another purpose, they send everything! But I don't want everyone to know, accidentally it might be released. So this is why I didn't tell anything so this is why the care was nice [...] If I said I don't know what would happen, so I cannot say:' ok this person I know is definitely a discriminating person or would refuse me,' no, I cannot say this because I don't know. But I didn't feel comfortable. I didn't feel comfortable to say, to declare my status. Her attitude might change, she may even refuse. Or even if she doesn't refuse, in my records if someone sees, I didn't want to declare this information. I find it's my personal thing.*"

This was a part of the first participant's narrative about his last visit to a dentist. Having heard stories of discriminatory reactions to his HIV positive friends, and having experienced a couple of unfavourable situations with the medical staff, he was afraid of being discriminated against or even refused by this dentist, and had concerns about confidentiality. He told me that he was completely comfortable to declare his status whenever he was referred to an experienced dentist by ACCM (see previous section). However, in this case he did not know the dentist and could not predict her reaction once she learned of his HIV status. Thinking that there was a "*50-50 chance*" that she would react negatively, he felt that he "*couldn't take a risk*" and decided not to disclose his status on the health questionnaire. This is a good demonstration of how some participants used disclosing as a strategy to cope with the apprehension of discrimination at a dentist's office. This participant considered his strategy successful: "*I don't have big problems as an HIV positive person because I'm hiding it*".

The issue of disclosing was brought up again and again in almost all interviews. All participants, even those who had little experience of discrimination or those who were open about their status, were unanimous that since HIV stigma still very much exists, they needed to be cautious about to whom they revealed their status. Yet each participant felt differently regarding disclosing to their dentists and everyone had his own reasons for and against disclosing, which I will try to summarize in the next paragraphs.

Firstly, it should be noted that some participants did not express worries over confidentiality or fears about being rejected by dentists. One participant was confident that dentists would not refuse him for legal reasons, and so did not feel the need to hide his status. And some participants were generally open about their status and believed that PLHIV should not be afraid to talk about it. That being said, some participants, even those open about their HIV status, believed that they had no legal obligation to disclose it to dentists. A couple of participants disagreed and considered that it was their responsibility to disclose their HIV so that the dental staff could take the necessary precautions to protect themselves. Consequently, when a participant chose not to disclose his status to a dental surgeon, he felt uncomfortable and guilty, especially after seeing how much bleeding was involved in the procedure. Some participants on the other hand, contested this argument of protecting the dentists, arguing that the professionals were responsible for protecting themselves and needed to take universal precautions.

We already mentioned that participants considered their HIV status to be a personal matter; they felt that the others did not need to know unless it was for a good reason: some questioned whether there was a good reason for a dentist to know. One argument in favour of disclosure was that the relationship between a patient and his dentist required openness and communication on both sides, which meant that the patient should tell his dentist everything related to his health. On the other hand, as discussed before, participants feared that HIV would overshadow all their health problems. For example, one hesitated to disclose his status at an emergency room because his health problem was unrelated to HIV, he was afraid that the doctors would fail to see his health beyond his HIV status.

Most participants thought that there was a link between their oral and general health and ideally their dentists should know about their HIV in order to take better care of their oral health. Those participants who chose not to disclose their HIV felt that they were losing out on this advantage despite gaining a sense “confidentiality”. And some of those who decided to disclose, never felt quite comfortable answering the question about HIV on the form. They wondered why the professionals asked this question and how they would use this information. In sum, the moment a person living with HIV faces this question, he has to think it through and consider the perceived social and personal impacts of his decision before deciding to respond. No matter what this decision may be, it could accompany feelings of discomfort, anxiety, and guilt.

5. DISCUSSION

Our findings reveal that the participants struggled with imperfect oral health, which they tried to maintain in order to remain functional and to prevent further loss. Meanwhile, their ability to seek oral health was more limited due to HIV, whether because of barriers such as costs (especially since finding a job and working full time is more challenging for a person living with HIV), or because they felt that they had limited choices of dentists, worrying that some dentists might refuse them or treat them differently. Consequently, our participants faced an anxiety about how to manage their oral health in years to come.

However, this is not the whole story of our participants. The story of our participants at the dental office does not begin at the office of the dentist. In Heidegger's philosophy the present is never an isolated "now". Understanding an experience might be done in the present moment but it is always done relative to past experiences; the past experiences pull the individual forward into the present "now" (119). To understand how a person living with HIV is experiencing his dental visit, one should understand his past experiences. Every patient with HIV that comes into the dental office comes with a history, not only the history of a person living with HIV, but also the history of HIV. Interviewing our participants was like an introduction into the history of HIV. They talked about their experiences in the 80s and 90s, when having HIV meant facing a "death sentence" and the fear of HIV/AIDS was rampant in the society, and about the perceptions of people towards PLHIV changing throughout the years. They discussed the advances in HIV treatment and compared the new medications with the previous ones with their side effects. Some of them were still living with the side effects of the first HIV medications, such as the changed and recognizable lipoatrophy of their faces. They carried the anticipation of rejections they faced decades ago just like they carried the side effects of the old generation medications and the years of living with an eroding illness. They carried that history of HIV with them and they were still influenced by this history. It is important for the dentist to understand not only the story of the patient living with HIV as an individual, but also the history of HIV.

In this chapter, I will first look at the struggle of PLHIV with oral and general health and how their lifeworld is shaped by this struggle. Then I will look at the relationship of our participants with dental staff by exploring HIV stigma, what it means, and how it influences the experience of PLHIV. Next, with the help of our findings and the narratives of the participants, I will endeavour to answer the question: “what are the characteristics of a good dentist for PLHIV?” And finally, I will close this chapter by suggesting recommendations for different sectors of the society to improve accessing dental care for PLHIV in Quebec.

On Health: Suffering, Loss of Wellbeing, and Anxiety

To live with HIV is in part to live with a chronic illness. Chronic illnesses are illnesses that are prolonged in duration and they are rarely completely cured (120). If we want to understand the experiences of PLHIV we should understand what it means to live with a chronic illness. In many ways, the findings of our study are congruous with studies that explore the meaning of life with chronic illness (120-122). Although the research done on this topic is mostly disease specific, there are commonalities between the experiences of those living with different types of chronic illness (122, 123). In the paragraphs to follow, we are going to look at the most significant of these features that were shared by our participants. Then we will explore “suffering” as a phenomenon that connects all these features and is one of the essential elements to our participants’ experiences.

A prominent feature of living with chronic illness is a changed experience of the lived body; it is common to experience profound bodily fatigue, restricted bodily functions and to feel physically fragile and vulnerable (120, 121). Similarly, our participants struggled with fatigue, living in fragile health, and limited physical abilities. In relation to their oral health, our participants experienced a sense of loss and disrupted bodily functions due to their poor oral health. They had to be careful with or mindful of what they ate, how they chewed, and how they swallowed. In other words, they noticed functions such as chewing, eating, and swallowing that usually remain unnoticed and out of awareness. Gadamer in his book *The Enigma of Health* (124) argues that illness can make us insistently aware of the bodily nature by creating a disturbance in something that normally completely escapes our attention. In health the body is taken for granted in everyday life, but in illness it “loses its silence” and can no longer be taken for granted; there is a deep sense of loss of bodily integrity. Gadamer thus describes wellbeing as a condition of not noticing, and of being unhindered and being ready and open to everything (124). Because wellbeing precedes illness in existence, its existence is mainly noticed in its absence (124). In the case of our participants, oral diseases such as caries and xerostomia disturbed the silence of their bodies and their orientation towards the world as they experienced their bodies in a different way than expected. Consequently, they noticed the absence of wellbeing and felt a sense of loss.

Experiencing the body as weakened, unpredictable and vulnerable could induce fear and anxiety in the individual (120). Individuals living with chronic illness may experience feelings of uneasiness about the progress of the illness and worry about how they will be able to manage an insecure future and they might even fear death (121). It is suggested that the experience of terminal chronic illnesses is quite unique and different from illnesses that are chronic but not life threatening (122, 123). Although this might not be the case anymore, some of our participants were diagnosed with HIV at a time when it was equal to –what they called- a "death sentence". Even with the recent advances in HIV treatments, having HIV means that the person's health is fragile and vulnerable, and life could suddenly change with a downfall of health. Having such knowledge engenders a sense of anxiety and fear and this affected the lives of our participants. They had to be careful and do the best they could to constantly monitor their health, including their oral health, and to maintain their functionality. The participants used the words "fear", "concern", and "worry" to describe their feelings about their health. I used the word "anxiety" to best describe this phenomenological element of anticipating something dangerous and unpleasant. Anxiety is created when the individual experiences a significant breakdown and doesn't feel at home and comfortable in the world (119). To understand how anxiety impacts the individual who experiences it, we could look at the work of Heidegger who has written extensively about anxiety. According to him, anxiety is a general mood experienced against something unspecified, mainly something threatening the individual's very own existence (unlike fear which has a known and specific object –such as spiders- and is extinguished once the object is removed). The diminishing health, accelerated aging, and the "death sentence" mark associated with HIV/AIDS, brought aging and death into focus for our participants, leading to high levels of anxiety. Heidegger suggests that anxiety exposes the individual to vulnerability and loneliness, and pulls him out of his absorption in the world in which he existed feeling comfortable and at home. The individual feels thrown into a darkness that is anxiety where he feels disrupted and bewildered. He no longer feels at home, he thus begins to feel uncanny and strange in the world (87, 119, 125).

Another common feature of the experience of living with chronic illness is struggling with self-perception and social identity; this was also confirmed by our findings. The individual living with chronic illness may feel left out and isolated because of his limited ability in doing activities. Restriction in physical and social activities results in a diminished lifeworld that challenges the individual's self-esteem (120, 121). Furthermore, the individual may experience a change of his role in society and feel that his true identity as a full member of the society is threatened by the reactions of others towards his illness. Therefore, he fights against being identified as a sick person and struggles to preserve his identity (120). Chronic illnesses such as HIV that force a dramatic change in the life course of a person are more likely to pose social challenges to the individual and therefore to his self-perception and identity (122, 126). This was also the case with our participants who felt that their various general and oral health issues isolated them and challenged their self-esteem and social identity.

To sum up, our findings reveal that similar to people who live with a chronic illness, our participants struggled with a changed experience of their lived body, an anxiety in the face of an unpredictable future, and a challenged social identity. It is best to understand this struggle under the umbrella phenomenon of "suffering" as it encompasses all these challenges. Suffering is the state of distress associated with events that endanger the person's intactness (127). It is not only the feeling of pain, but also the fear of pain, the discomfort and anxiety (128). As Freud writes, "we are threatened with suffering from three directions: from our own body, which is doomed to decay and dissolution and which cannot even do with pain and anxiety as warning signals; from the external world which may rage against us with overwhelming and merciless forces of destruction; and finally, from our relations to other men (129)"

According to Öhman, living with chronic illness is to live a life "hovering between suffering and enduring" and thus suffering is an essential element of life with chronic illness (121). Enduring is the response of a person when they have no choice but to go through what inevitably exists, whereas suffering can gradually reduce over time. Once the individual has accepted what he has endured, suffering begins to fade. This process includes a reformulation of self in a "struggle for normalcy", which means that the individual had learned to live with the new life as a person with a chronic condition and to integrate the change (121). Charmaz in her extensive work on chronic illness suggests that adapting is one way of living with impaired bodily functions. Individuals adapt in the face of physical loss to regain a sense of wholeness of body and self (130). This process includes the reformulation of self and therefore a struggle with identity that is an essential part of life with chronic illness (120). As our objective was not to study the experience of life with HIV, it was beyond the scope of our study to explore the trajectory of our participants' lives. Nevertheless, this process of reformulating the self and "struggling for normalcy" was evident in the narratives of our participants. Since they had lived with HIV for many years, it was possible that they had already accepted what they had endured and moved beyond their suffering. They were probably at a stage where they had reformulated their sense of self and at the time they were struggling for normalcy by managing their health as best as they could. Hence, instead of suffering I picked the word "struggling" to describe the essential element in the experience of our participants, yet it should not be forgotten that suffering was at the core of their lives with HIV.

Suffering in itself is a distinct phenomenon and all the different and various painful experiences we previously discussed are connected together by the "suffering mood". Unlike emotions, moods do not carry specific thoughts or perceptions but they reside in the background escaping our attention. Heidegger as well as other philosophers introduce moods as meaningful experiences that influence the way the world opens to the person (125). Svenaeus suggests that suffering is a mood that has implications for the person's entire life and how he understands and communicates with the world (125). This finally brings us back to our findings, where we see how the perceptions, attitudes, and behaviours of PLHIV are affected by life with HIV and their suffering. If one seeks to understand the world of PLHIV, they must understand the suffering that has shaped their world.

Therefore, I believe it is important for dentists to understand the suffering experienced by HIV positive patients because their suffering affects how they perceive the world. Based on this I would like to suggest that a patient-centred care model is an ideal model for providing dental care to patients with HIV. There are ambiguities regarding a universal definition of patient-centred care but its components include humanizing the patient and understanding the patient as a whole person, seeing the illness through the eyes of the patient, giving information to the patient and to reach common grounds in making decisions, being responsive to the patient's preferences and wants and needs, and improving doctor-patient relationship (131, 132). Patient-centred care is holistic, in other words it is attentive to patients' psychosocial as well as physical needs (131, 132) and seeks to understand not only the patient's disease, but also his illness through understanding his suffering.

Most of our participants suffered from other conditions in addition to HIV, yet they felt that their health was sometimes overshadowed by HIV. HIV could be only a piece in the life and health of the patient and it may not always be the dominant or most pressing condition for the patient, so the dentists should take the priority of the patient into consideration. Patient-centred care is responsive to the priorities of the patient and is ideal for those living with multiple conditions (133). It also involves a mutual participation of patient and doctor in the decision making process (131). Adopting a patient-centred approach towards healthcare empowers the patient who is already in a vulnerable position, in particular those who belong to vulnerable groups in the society such as PLHIV. Furthermore, people with chronic illnesses become experts of managing self-care and it is suggested that they should be able to actively participate in making decisions on their health (122). Self-care management is therefore crucial for PLHIV especially because it is consequential in their struggle for normalcy as previously discusses. Because patient-centred care involves the patient in his health care and allows him to have control over managing his own health it is ideal for HIV positive patients.

On Dentist-Patient Relationship: Otherness and HIV Stigma

The predominant aspect of our participants' experience in relation with the dental staff could best be described by the concept of "stigma". HIV/AIDS related stigma is a complex phenomenon (104) with various dimensions that change through time (59) and across different sociocultural contexts (134). There are several HIV/AIDS related stigma frameworks and I will try to make use of the leading ones to best illuminate the experiences of our participants with respect to HIV stigma.

PLHIV are subjected to numerous forms of stigmatization (59). Most stigma frameworks do not differentiate between the three manifestations of stigma: prejudice, stereotyping, and discrimination (135). Prejudice refers to the emotional aspect of stigma and the negative feelings held towards the stigmatized. Stereotyping is the cognitive aspect of stigma, generally in the form of negative beliefs held about the stigmatized. Finally discrimination is the behavioural expression of stigma (135). Our participants alluded to all these aspects of stigma, but what they most commonly described was the negative or "uncomfortable" feelings or the fear and dislike they sensed in the attitudes of others towards themselves, in other words prejudice. Therefore, our participants were most sensitive to how the other person including the dental professional felt about HIV and PLHIV and they believed that they could somehow sense or feel prejudice even though it might not have been enacted.

The participants did not refer to stereotyping as often as they did to prejudice or discrimination, however they believed negative stereotypes such as the association of HIV with reckless sexual behaviours and drug use and poverty was partly responsible for the prejudice they experienced. This shows that PLHIV could be the subject of different stereotyping and stigmas in addition to that of HIV. It is suggested that those who are more homophobic and have less knowledge about HIV/AIDS transmission are more likely to have stigmatizing attitude towards PLHIV (59). Similarly, many participants blamed homophobia to be responsible for the prejudices of some people towards PLHIV, especially outside the gay community. Likewise, our participants believed the fear of HIV transmission and lack of knowledge about HIV and HIV transmission to be behind some of the prejudice and discrimination they faced, especially within the dental settings. In this case some participants made a distinction between dentists and other healthcare professionals, such as family physicians and pharmacists, considering that dentists work directly with blood. And because –as already discussed in the findings- participants were familiar with universal precautions and the low transmission rates of HIV in dental procedures they made an inevitable conclusion that the dentists who held fears about HIV lacked knowledge about HIV transmission.

The participants commonly blamed the fear of HIV as a deadly disease for the prejudice against PLHIV and they also associated this fear with a lack of knowledge about HIV. As a few participants mentioned, some PLHIV are sensitive to others confusing HIV with AIDS. They explained that as AIDS was once a death sentence and this image and the fear of this image still persisted. It is thus important to differentiate between HIV, which to them was "just a virus", and "manageable" condition, and AIDS. They believed that failing to do so showed a lack of knowledge and it was particularly unacceptable for a healthcare worker. This is evident in this narrative of one participant about the interaction of his friend with a medical doctor:

> "*And he pulls the curtain and says so how long have you had AIDS? My friend looked at him and said: 'don't you know the difference between HIV and AIDS? And you call yourself a doctor?' He was pissed, but for that generation it's still like 20 years behind, it's an old disease, you know way from gays and heroin addicts. And that*

> *happened like 4-5 years ago. It's scary because you are dealing with people in the medical field. Imagine somebody they just have no knowledge they get scared like crazy.*"

Because the cognitive part of stigma could in some cases be responsible for the prejudice against HIV, education on HIV and HIV transmission and universal precautions could help in reducing HIV stigma, especially fear and discomfort in dental care providers.

Discrimination occurs when stigma is acted upon. It is defined as any form of arbitrary and unjustified distinction, exclusion, or restriction that affects the stigmatized (104, 136). I'm going to use a mix of two framework adapted by Steward et al. (137) and Mahajan et al. (104) to delve deeper into the experience of participants with stigma and specifically with discrimination.

Steward et al. defined four facets of stigma in their study: enacted stigma, vicarious stigma, felt normative stigma, and internalized stigma (137) (or perceived stigma (104)). The two former definitions are the interpersonal forms of stigma and the two latter capture its interpersonal components (137). Enacted stigma is the overt acts of discrimination towards PLHIV. Vicarious stigma is the stories told of discrimination against other PLHIV, which was later added to the framework because the researchers found that vicarious stigma was influential on the perceptions of their subjects. Internalized stigma refers to the degree to which the individual accepts HIV stigma as legitimate. Internalizing stigma by the stigmatized results in self-stigma (137). Felt normative stigma is the subjective awareness of stigma, or the extent to which stigma is felt as normative phenomenon (137). According to Steward et al. felt normative stigma will motivate individuals to take measures to shield themselves from enacted stigma (137).

Mahajan et al. in a review of literature on HIV/AIDS stigma draws attention to three dimensions of discrimination in specific: self-imposed discrimination, individual discrimination, and structural/institutional discrimination (104). Self-imposed discrimination occurs when the individual anticipates stigma and out of the apprehension of being discriminated, a priori behaves as if discrimination has already been established. Individual discrimination is the overt act of discrimination by one person against the stigmatized, whereas structural discrimination is the "accumulated institutional practices that work to disadvantage stigmatized groups, and can work in the absence of individual prejudice and discrimination" (104).

Using terms derived from these two frameworks, I will try to describe the experience of our participants with respect to discrimination. In general, they reported relatively little encounter with individual discrimination or enacted stigma in dental settings. Similar to the results of Steward et al. (137) (in a survey of stigma measures based on their framework and given to 229 PLHIV in India), our findings suggest that vicarious stigma or the stories the participants heard of negative experiences other PLHIV with dental staff contributed significantly to the perceptions of our participants. Although to a lesser extent, enacted or vicarious stigma in other social contexts, particularly within other healthcare settings, had a similar impact. This impact was that they felt an anxiety or apprehension of being stigmatized because they perceived stigma to be out there and possible. This could be compared with what Steward et al. refers to as felt normative stigma. This anticipated stigma or felt-normative stigma occasionally led to self-imposed discrimination that had the potential to limit the participants in their access to care, for example by avoiding going to some dentists or clinics or seeking treatment because they feared being stigmatized. In addition to self-imposed discrimination, some participants revealed a degree of internalized stigma in their narratives. The outcome of internalized stigma was evident in their lowered expectations from dentists and adapting an accepting attitude towards discriminatory behaviours from their dentists. Self-stigma also added to participants' feelings of anxiety and guilt as they felt the need or responsibility to somehow protect the dental staff from HIV or when they felt uncomfortable discussing their condition fearing that other patients would hear them and would boycott the dentist because he was treating PLHIV.

Little research has been done to measure and target institutional stigma (104). From a legal perspective, HIV and AIDS are considered disabilities under the law. Canadian human rights laws prohibit service providers from discriminating against people with disabilities and therefore dentists are not allowed to refuse patients based on their HIV positive status (118). However, addressing institutional discrimination in dental settings is a complicated matter that requires further investigation. I believe our findings provided a good example of how structural discrimination can influence PLHIV's access to dental care. As discussed earlier, PLHIV experience fatigue and unstable health conditions that requires flexibility in their working schedules and not many working environments accommodate the needs of PLHIV. Many participants had a difficult time finding and maintaining work because of their health or because of enacted or anticipated or self-imposed stigma. The institutional discriminations that makes working conditions difficult for PLHIV means that many PLHIV, such as our participants might struggle financially and consequently, may find costs to be a major barrier to accessing dental care.

All this being said, an attempt to build an understanding of stigma will not be complete without referring to Goffman's classic work, which is considered to be one of the first sociological works on stigma and the departure point for discussions of stigma and HIV stigma (134, 138, 139). Goffman opens the first chapter of his influential book *Stigma: Notes on the management of spoiled identity* (140) with the etymology of the word stigma:

> "The Greeks, who were apparently strong on visual aids, originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, criminal, or a traitor- a blemished person, ritually polluted, to be avoided, especially in public places […] Today the term is widely used in something like the original literal sense, but it applied more to the disgrace itself than to the bodily evidence of it (140)."

Therefore in the old and new sense of the word, stigma is a marker of a tarnished character within social relations. Goffman views stigma as an "attribute that is significantly discrediting" (140). An individual that possesses such an attribute might find that this particular trait obtrudes itself upon attention in social relationships, stealing the attention from his other attributes. As a result, the stigmatized individual may find that his stigmatized attribute reduces him "from a whole and usual person to a tainted and discredited one" in social interactions (140). This description is particularly salient in understanding the experience of our participants, as some believed that HIV overshadowed their identity and became their defining feature in the eyes of others. Furthermore, some felt that in some social interactions they were dehumanized and reduced to "the HIV guy" or even a "second class citizen" because of HIV. This process can push the stigmatized into isolation from the society, even though the stigmatized can find support groups to learn tricks of the trade about how to navigate through the society. In these groups, people help each other to live as "normally" as possible and stay within spheres in which they can feel "normal" (138). ACCM had a similar role for our participants: it provided them with help to navigate through the health care and dental care systems despite HIV stigma. The list of trusted dentists or the blacklist of professionals who had stigmatized some members, or any way in which the ACCM members exchanged their negative or positive experiences at the dentist's office with each other, were examples of our participants seeking to create a safe sphere where the members could navigate as "normally" as possible within dental healthcare system.

A key strategy of managing stigma in Goffman's conceptualization of stigma is known as "passing", which he describes as "the management of undisclosed discrediting information about self" (140). According to Goffman a person who possesses a stigmatizing attribute is either discredited or discreditable. The discredited are socially judged and marginalized based on the stigma, whereas the discreditable have not yet been discredited mainly because their stigmatizing attribute has not been divulged. Thus, socialization for the discreditable is a process of information control in which he constantly manages the signs of his stigmatic attribute. Passing is when the discreditable tries to "pass" as normal, namely as someone without the stigma (140); in other words, passing is simply choosing not to disclose the invisible stigma. The reluctance of some participants to disclose their HIV positive status to their dentist could in part be explained by the process of "passing". Choosing whether or not to disclose to a dentist is a means of information control to avoid being discredited. As participants experienced anxiety over HIV stigma and did not feel in control of how they might be treated, they sought to pass as "normal" and regain control over the situation by not disclosing their HIV.

The visible signs of HIV such as facial lipoatrophy (117) could impede PLHIV from successfully passing. They may try to hide these signs, for example by considering injections to fix the flattening of their faces (lipoatrophy) like a couple of our participants. However, because of the oral manifestations of HIV (26), dentists have access to otherwise invisible signs of HIV, making it challenging for some PLHIV to pass. A participant shared the story of a friend who did not disclose his status to his dentist but because of his severe candidiasis the dentist suspected HIV and questioned him. Once he admitted to his positive HIV status, the dentist recommended him to consult a more experienced dentist (as I discussed in the findings the participants suggested this technique as a form of polite refusal and discrimination).

The decision of those participants not to disclose to their dentists was affected to a degree by enacted stigma but mostly by felt normative and vicarious stigma. On the other hand, those participants who believed it was their responsibility to disclose their HIV so that the staff could protect themselves and felt guilty if they did not disclose were potentially driven by internalized stigma. As some participants mentioned, PLHIV do not have a legal duty to disclose their status with respect to the provision of health care, and healthcare providers are expected to take universal precautions to prevent being exposed to HIV and other blood borne pathogens (141). PLHIV should know that it is within their rights not to disclose their HIV status to a healthcare provider, especially if it is not relevant to the service they require (141). However, some participants chose to be open about disclosing their status in order to normalize HIV. In other words, PLHIV who hide their status are in a way allowing for the continuance of HIV stigma.

The dentists should be aware of the sensitive and complex nature of disclosing HIV positive status for the HIV positive patients, and thus approach this topic with the consideration and empathy it deserves. Our findings suggest that the participants expected scientific justification behind the behaviours of their dentists. When dentists ask about the HIV status of a patient they are "*always thinking why would they ask that, is it really relevant?*"- in the words of one of our research participants. Therefore, I invite the dentists and other healthcare professionals to carefully contemplate the reasons why they ask this sensitive information, instead of thoughtlessly and automatically putting HIV as a box to tick on a health inventory form.

Although Goffman's focus on stigma as a discrediting attribute has led to many conceptualizations of stigma as an individualized and static attribute, stigma is a constantly changing social process (139) (in fact Goffman himself was interested in the social construction of identities; he emphasized that the language needed to talk about stigma was a language of relationships and not of attributes (139)). Link and Phelan (142) conceptualize stigma as a social process involving four components. First, the individuals distinguish and label differences. This is followed by negative stereotyping, which is linking labelled persons with undesirable characteristics. Then the labelled individuals are placed in distinct categories, where "they" are separated from "us". And consequently, these individuals experience status loss and discrimination (142).

I selected the word "othering" to describe the essential meaning of the participants' experience of receiving dental care with respect to relationships. This was partly because the participants rather emphasized on being perceived as "different" as opposed to the negative outcomes of stigma such as discrimination. For instance, they mainly used the word "different" to explain how they occasionally felt treated, instead of describing it as "discrimination" or "stigmatization". Othering has been defined as the process of identifying those who are thought to be different from mainstream or oneself (143). This process can generate or reinforce positions of subordination and domination (143). As manifested by the framework suggested by Link and Phelan (142), to perceive someone as different, and to separate “them” from “us”, is a part of the stigmatizing process that eventually leads to discrimination. Consequently, “othering” becomes an essential part of establishing stigma, even if it is not acted upon. According to the German sociologist Gerhard Falk: “we and all societies will always stigmatize some conditions and some behaviours because doing so provides for group solidarity by delineating ‘outsiders’ from ‘insiders’”. He suggested that it is probable that all of us, even the educated and culturally advanced, are liable to perceive and treat someone differently because we see them as “outsiders” (144).

Parker and Aggleton also criticize individualistic approaches of targeting stigma and highlight stigma as a social process (139). Instead of conceptualizing stigma as an isolated phenomenon, they suggest that stigma functions at the intersection of culture, power, and inequality. Stigma can only be understood in relation to domination and power. Power is used to legitimize social inequality and it is necessary for enabling stigmatization. In turn, stigma helps to produce and reproduce relations of power and control. Stigma reinforces and reproduces, and is sustained by existing social inequalities, making some people feel superior to others while making others excluded. In this way stigmatization is a part of the complex structures of social inequality that persists and reproduces itself without giving rise to strong resistance. This helps us understand how the stigmatized accept and even internalize stigma, because they are subjected to a powerful system whose function is legitimizing inequality, based on different interpretations of merit and worth. The emphasis on stigmatization as a process associated with legitimization of social inequality, underscores the need for paying attention to the broader social (including economic, cultural, and political) forces that are behind generating and regenerating inequalities. Parker and Aggleton suggest that in order to break the chains of stigmatization and discrimination, we should question and re-evaluate the very structures of inequality in all social settings (139).

Those dentists who are truly on a quest to eradicate HIV stigma should not only stop at correcting their own prejudices and refraining from imposing individualized stigma on PLHIV. They should challenge institutional stigma through questioning and advocating for equality in the society, which is the feeding source of all stigma. As people in a relatively powerful position in the society and benefiting to a degree from social inequalities, dentists have the power and responsibility to address the structural inequalities within the society, in addition to battling HIV stigma in dental care settings. We as healthcare professionals sometimes tend to set ourselves apart from the society, believing that our responsibilities towards our patients stop behind the office door. However, as one of the participants articulated, the issue of HIV stigma in dental settings is not only a dental issue, it is a social matter:

> "*It's not only a dental issue, it's a social issue. Dentists are coming from this society and not only dentists, any healthcare professional can act like this, or any person, even the police, or fire fighters in person. And I cannot blame them because in the society there's a stigma and, discrimination is a bad word, but differentiate. So, I have an illness, which who cares, as a social person. And if society turns like this, dentists will be ok as well. But it's not only dentistry students' fault because their parents, their friends, they have this worry and if there are ten people around me and they're worried about HIV or they're scared of HIV, I will as one person by time I will turn like them and they will not like me, unless you took to power. So this is why dentistry students or dentists or doctors in this society, if the society doesn't change it will be the same thing.*"

The Ideal Dentist, According to Our Participants

In this section, we will discuss the qualities of an ideal dentist for PLHIV based on the findings and the descriptions of our research participants. We acknowledge that, what was written in the next few pages is only an incomplete profile of an ideal dentist. Thus, the descriptions provided in the next pages should be viewed as suggestions on how to become a better dental care provider for PLHIV, as opposed to a strict and comprehensive guideline, which could be a topic for further research.

> "*Honestly I don't want to undermine N but I'm not sure that he is the best dentist in the world. But he has the best approach for people living with HIV in my experience. He doesn't give a shit.*"

This quotation from one of the research participants highlights what many stated in one way or another. First and foremost, the "ideal" dentist holds no prejudice and stereotyping beliefs against PLHIV. In other words, as previously discussed in the findings, the ideal dentist does not care whether or not a person is HIV positive, or if he has any other stigmatized attribute like being homosexual or on welfare. He only considers HIV if it is for providing the best care for the person’s health. The ideal dentist feels comfortable and acts comfortable around patients with HIV and treats them with the same quality as any other patient.

Since most participants believed that fear of HIV transmission or lack of knowledge about handling HIV positive patients was responsible for stigmatizing attitudes of some dentists, they assumed that a dentist who is knowledgeable about HIV is less likely to stigmatize HIV patients. A knowledgeable dentist knows that he should use universal precautions for all patients, regardless of their HIV status, and uses the same safety measures for all. He knows that using these measures will protect him and his staff; for this reason, he is not be afraid of HIV exposure and can hence better focus on providing the best care for his HIV positive patients. Consequently, our participants trusted dentists who were experienced with HIV patients not only because they knew best how to attend to the PLHIV’s special oral health needs, but also because they were less likely to discriminate against them. If a knowledgeable dentist needs to treat the HIV infected patient differently than he would treat other patients, he can justify his decisions with scientific reasoning. He can also explain to the patients why it’s best if a dentist knows about the patients’ HIV status. And in fact, all participants understood and appreciated it when they were offered explanations from their dentists.

A knowledgeable dentist knows how to diagnose and manage basic oral manifestations of HIV. This prevents situations similar to the ones a couple of participants had experienced, where their healthcare provider's lack of knowledge about HIV led to additional and superfluous steps in their treatment plans. For example, one participant’s dentist ordered an unnecessary biopsy of an oral lesion, whereas another was referred to an HIV specialist for a consultation before a simple procedure, only to find out that such precautions were unneeded. A knowledgeable dentist can also tell HIV positive patients about the importance of oral health for PLHIV and the special considerations they may need to take. It is best if dentists who are knowledgeable about HIV and experienced with treating PLHIV to collaborate with HIV communities and organizations, so that PLHIV can access them more easily. Participants were also more trusting of dentists that their communities recommended.

Participants unanimously emphasized on the significance of the patient-dentist relationship. They perceived dentists as indispensable and pivotal assets of the healthcare system, and the dentist-patient relationship as one of the most important relationships they had in healthcare settings. Most participants preferred not having to switch dentists and had the tendency to stay with dental professionals for a long time, making the importance of establishing a strong relationship even more prominent. An ideal dentist builds a strong relationship with his patient based on trust, communication, a reassuring behaviour, and a caring and humanizing attitude towards the patient. The research participants wanted a safe and understanding environment in which they could openly share their "stories" with their dentists; a place where they would be guided and helped with taking better care of their oral health instead of being judged or blamed for their health problems, especially considering the challenges with the upkeep of a good oral health condition for PLHIV.

Above all the participants wished to be treated with sincere concern, empathy, and an overall genuine approach by their dentists. A humanizing attitude becomes particularly consequential for providing health care to PLHIV, who come to the dentist's office with experiences of having been subjected to dehumanization in various social settings. Participants appreciated it when their dentists showed interest in them by genuinely listening to them and engaging in a conversation. They wished that their dentists would ask about their general health and wellbeing, beyond their dental health problems and their HIV status, in a way that showed sincere care and concern for them as a person (on the other hand focusing on questions about the HIV status such as the viral load of the patient implies that the dentist is mostly concerned for himself and his own safety). Visiting the dentist could be a stressful experience for many people, especially if they are about to experience the loss of their teeth or have a complicated and expensive treatment. And on top of that, PLHIV constantly struggle with various general and oral health problems and experience anxiety over their oral health. Having a caring and reassuring demeanour would help the patient feel more at ease and comfortable at the dentist's office. In fact, being reassuring was one of the main qualities of a good dentist for the participants. A reassuring professional is not only good at comforting patients about their worries and concerns over their health, he also signals that he is comfortable around them and he also appears more professional.

Trust was key to the participants in their relationships with dentists and other healthcare providers. Being knowledgeable about HIV, having a non-stigmatizing attitude, and being sensitive to the specific needs and concerns of PLHIV such as respecting their confidentiality are essential in establishing trust between a dentist and his HIV positive patients. Enhancing communication is also a major contributor to trust and to a strong dentist-patient relationship.

Our participants were actively involved in managing their health and it is suggested that patients with a chronic condition participate in the decision-making process regarding their health (122). In this perspective, communication is fundamental because sharing knowledge with HIV positive patients could allow them to participate in their own health care. The ideal dentist presents all possible treatment options to the patient so that they could reach a joint decision, which is what many participants wished for. Conversely, if the dentist takes a paternalistic approach to care, positioning himself as the expert and the decision-maker (132), he excludes the patient from the management of his own health, which is very important to PLHIV. And as one participant suggested, a dentist or doctor with a paternalistic approach may give off the impression that he stereotypes PLHIV as people who are not capable or organized enough to take care of their own health, and thus stigmatizes towards HIV positive patients.

Last but not least, an ideal dentist should be a part of the public health system in Canada. Many participants shared the perspective of this participant who suggested: "*I would make it [dental care] in the health system. I think it should go together.*" The participants considered that dental health is a part of general health and thus dental care should not be separated from the general public healthcare system. Participants enjoyed their experience of receiving dental care when the dental staff collaborated with the medical staff as a part of one group. Thus, they preferred a more holistic approach to dental care than it is currently offered in dental offices. They also wished dental services to be covered by the public health insurance so that it could be accessible to all, especially considering their difficulty due to the high costs. Furthermore, a participant thought that because dental care involves a direct transaction of money between patients and dentists, the relationship between a patient and his dentist becomes less about the interaction between two humans and more about a business transaction compared to the relationship with his family physician.

To summarize the question about "who is a good dentists for PLHIV", I will quote a participant describing an ideal dentist:

> "*Somebody who's going to be listening to me, be more attentive to my condition my health, not being afraid of asking questions about HIV, about if I had other like diabetes for example, being open minded and proposing stuff, not just saying ok we're going to repair this it's going to cost you 2000 dollars for one tooth. My ideal dentist will*

> *come with options, and will not be afraid of touching me and do the work that he needs to. That's the ideal, it could be free, my ideal dentist will be free.*"

Study Strengths and Limitations, and Directions for Future Research

Interpretive phenomenology was the chosen methodology for this study and it proved to be suitable for our purpose, which was to gain a better understanding of what accessing dental care means to PLHIV. The qualitative element of this study added to the strength of our research by allowing us to collect rich data about the topic of interest. Our findings confirm that the lived experiences of PLHIV are rich and complex and these complexities were captured by a phenomenological approach that provided a deep and insightful means of gaining an understanding of the experience under enquiry. Many of the research participants were struggling with various health problems such as hepatitis, diabetes, mental illness, and drug abuse; as well, many were facing social challenges of being unemployed and on welfare or being homosexual. The diversity of these challenges added depth and transferability to our study and other health situation for people living with HIV. Additionally, by taking a participatory approach we engaged members of the community in our research. I believe that this not only added to the credibility of our findings, it proved to be extremely helpful throughout the course of our research. The real-life experiences of our co-researchers from the community added to our methodological and academic expertise to make this research more complete, and hopefully it will prove to be useful in the knowledge translation process.

Along with its obvious strengths, a phenomenological approach of enquiry brings about discussions about certain limitations. Relatively small sample sizes are not uncommon in qualitative research, especially in phenomenological studies (81). Our sample of eight participants may seem to be a limitation of our study. While it could be argued that more interviews may yield richer data, eight interviews were deemed to be sufficient in our study and provided us with rich interpretive material.

We conducted this study in Montreal, a multicultural metropolis in Canada. As many participants pointed out, living in such a city influenced their experiences of receiving dental care and their lives in general. Therefore, our findings may not be generalizable to other social contexts. However, the experiences of PLHIV in other contexts possibly share similar elements with that of our participants. Therefore, our results could be transferred to other contexts, providing that the researchers take the social and political similarities and differences between the two contexts into consideration.

The participants were all white men between 45 and 55 years of age, and except one were all Canadian-born. Despite trying, we could not recruit female participants in the timeframe of our study. This means that our study does not offer a female perspective of the phenomenon of enquiry. Our sample was also limited in incorporating people belonging to various ethnic groups in Canada, particularly the aboriginal communities, or younger age groups. It is acknowledged that the homogeneity of our sample in terms of gender, ethnicity, and age means that our findings may not be automatically transferred to the general population.

Furthermore, all our participants had been diagnosed with HIV for numerous years, so our findings do not include accounts of people recently diagnosed with HIV. This is important for two reasons. First, the experience of living with HIV at the present time may be very different compared to the 80s and 90s, when HIV, perceived as a death sentence, was more feared and stigmatized. Second, the passing of the years might have limited or altered the ability of the participants to recall their experiences when they first accessed dental care as someone living with HIV.

Our interview questions did not delve deep into the rich and complex personal history of our participants. The participants occasionally brought up their background stories, especially from around when they were first diagnosed with HIV, showing that their experiences were somehow shaped by their backgrounds. Nevertheless, I could not enquire further into these stories because of the limitations in the time and scope of a Master's thesis. I acknowledge this and suggest that future researchers explore further into the backgrounds of PLHIV.

Future research should attempt to incorporate the perspectives of women, people from different ethnic backgrounds and minorities particularly those from aboriginal communities. In addition, interviewing participants recently diagnosed with HIV may yield different findings. Participants also called for gathering data from those living in smaller cities, where they thought people were subjected to more stigmatization while having a more limited choice of dentists. A future direction based on our findings could be devising and testing guidelines for dentists and frameworks specific to dental settings. Our findings could also be used in mixed methods studies for measuring HIV stigma in dental settings in a large and diverse sample. Because of the scientific advances in treating HIV, the experiences of PLHIV changes constantly; additionally, stigma is not static but rather a dynamic social process. Therefore, studies should be performed regularly to keep up with the ever-changing problems and needs of PLHIV.

Suggestions

Our research reveals that PLHIV struggle with their oral health, and yet face barriers accessing the dental care they need. As these barriers are mainly socially constructed, it is fair to invite the different sectors in the society to strive to alleviate them. Based on the findings of this study we are making recommendations for four target sectors: policy makers (including the government, the dental associations, and the Order of dentists), dental schools (including educators and researchers), dentists (including the dental staff), and the organizations and communities for PLHIV (such as ACCM and COCQ-SIDA).

The Canadian Charter of Rights and Freedoms, as part of the Constitution of Canada, guarantees equality of rights and freedom from discrimination for everyone living with a disability, including HIV/AIDS. This means that PLHIV have constitutional protection against discrimination. The Canadian government is thus responsible for implementing and enforcing anti-discrimination policies and raising awareness of these legal protections. The government should collaborate with HIV communities to advise PLHIV about their rights. The government has the power to reduce the financial barriers to accessing the much-needed dental care for PLHIV and should therefore aim to do so, for example by designing dental insurance plans for the specific needs of PLHIV. The Order of Dentists of Quebec (ODQ) also has the power to make anti-discrimination policies and oblige dentists to apply these policies in their practices. The ODQ being responsible for evaluating dentists, should measure HIV/AIDS stigma in dental offices and devise guidelines for treating PLHIV for dentists to follow. Furthermore, the ODQ should provide continuing education programs for dental professionals in order to raise awareness and improve their knowledge and skills about HIV and managing HIV positive patients. The ODQ along with the government should ensure that PLHIV have access to HIV knowledgeable dentists, particularly in smaller cities. They should consider establishing mobile dental clinics for providing dental care to the underprivileged and vulnerable populations including PLHIV.

Dental Schools and Faculties across Canada play a crucial role in educating the future dentists about their responsibilities with all patients. Dental students need to learn more about

HIV and managing HIV positive as healthcare professionals. Dental Schools and Faculties need to include programs for treating special needs patients, including PLHIV, in their curriculum. The dental schools could also establish postgraduate and specialist programs in special care dentistry. The students should partake in outreach programs, where they can attend to HIV positive patients in their own communities. In addition to increasing the accessibility of dental care for PLHIV, this will benefit the students in terms of their education. Dental schools should also focus on humanizing dental care, and shift from teaching biomedical and paternalistic models of care to a patient-centred model.

As most research done in the field focuses on the perspectives and attitudes of dentists and dental students as opposed to PLHIV, we invite researchers, especially researchers in the field of public health to work more on the needs and perspectives of PLHIV. Researchers should work in collaboration with community organizations to empower PLHIV and to gain a better understanding of the experiences and needs of PLHIV regarding accessing and receiving dental care. We encourage researchers to work with communities and experienced dentists to design guidelines for managing HIV positive patients.

As the main sector that works directly with patients, dentists are the ones ultimately responsible for providing the best and most accessible dental care to PLHIV. Previously I proposed that dentists should take a patient-centred approach for providing the best dental care for PLHIV. I also put forward that dentists, in collaboration with other sectors of the society, should tackle HIV stigma in dental settings by fighting stigma and inequality in the society at large. Additionally dentists should take upon themselves to acquire knowledge about the special oral healthcare needs of PLHIV and gain experience about managing HIV positive patients. Dentists should work together with other healthcare professionals to provide optimum care for PLHIV. They should respect the rights of PLHIV regarding equality and treat them accordingly and educate their staff to do the same. They are responsible for using universal precautions to protect themselves and their staff. We invite dentists to recognize the many challenges faced by PLHIV and to adapt a patient-centred approach in treating HIV positive patients. This implies that dentists should learn to carry out conversations with their HIV positive patients, to understand them and their needs and be flexible to accommodate these needs. Furthermore, they should be sensitive of the PLHIV's need for confidentiality. Therefore, we encourage dentists to take extra precautions in storing the files of PLHIV and to specify a closed private space to discussing the health issues of their patients. The dentists who are skilled in treating PLHIV should work with communities to ensure that their services are more readily accessible for PLHIV.

Communities and organizations of PLHIV should keep advocating for the rights of PLHIV and educating the members about their rights. They should continue fighting institutional stigma and offer their support to members in their battle with discrimination. Communities should educate their members about the significance and management of oral health for PLHIV. They can organize talks by dental professionals or arrange meetings for members to exchange their experiences and knowledge about their oral health and receiving dental care. We invite communities and organizations to communicate and collaborate with dentists and dental faculties in areas of education, research, and healthcare services. They should continue providing lists of experienced and knowledgeable dental professionals for their members and they should inform their members about the existence of such lists.

6. SUMMARY AND CONCLUSION

Summary of Our Objectives and Findings

As reflected in our research objectives, my initial motivation for taking on this project was to offer researchers, dental students, and especially clinicians such as myself an in-depth understanding of the experiences of patients living with HIV who seek dental care. I believed that such understanding could make dental professionals more sensitive towards the needs and challenges of their HIV positive patients, hoping that eventually this would make dental care more accessible to PLHIV who struggle with obtaining the dental care they need.

This study achieved its objectives by employing an interpretive phenomenological approach inspired by van Manen's phenomenology of practice. Phenomenology was particularly appropriate for providing us with a deep understanding of complex and sensitive experiences of PLHIV. Additionally, phenomenology, and phenomenology of practice in particular, is suited for providing an opportunity for healthcare practitioners to reflect on the complexities and subtleties of the experiences of PLHIV, and to evoke their treatment of PLHIV in their practices. In the two paragraphs to follow I will summarize our research findings centred on the two main themes of "oral health" and "patient-dentist relationship" and the essential elements of meaning that emerged from them. Based on each of these essential meanings I made two key suggestions for dentists that address our final research objective.

Having HIV significantly shapes people's experience of dental care. It not only affects their oral and general health, but also impacts their attitudes towards oral health, meanwhile limiting their access to dental care. Like other chronic illnesses, HIV causes fatigue and limits the abilities of the individual. This may in turn prevent PLHIV to partake in various social and professional activities. Their limited ability to work has significant repercussions on PLHIV's access to dental care because of its high costs. Additionally, the fatigue and struggle with many health issues could occasionally prevent them from seeking dental care altogether. PLHIV experience many anxieties and vulnerabilities when it comes to their oral and general health. They feel that their fragile oral health could go downhill and are afraid not being able to manage their health in the future and remain functional. In essence, PLHIV experience suffering from these fears, loss, fatigue, and limitations. It is important to understand the suffering of PLHIV as suffering shapes their worlds and their perceptions and general attitude towards their health and the others. Despite the suffering, PLHIV try to return to normalcy by managing their health and it is particularly important to them to feel in control of their health. In order to address this need and to be more responsive to the suffering of PLHIV, we suggest that dentists take a patient-centred approach in treating PLHIV that seeks to understand the psychological needs of PLHIV and involves them in the decision making process of their care.

Another aspect that limits PLHIV's access to dental care and adds to their oral health-related suffering and anxiety lies in the stigmatization they face in their interactions with dental professionals. Although our participants were generally satisfied with their dentists, they experienced episodic instances where they felt that the dental professionals were stigmatizing towards them. These instances mostly comprised subtle expressions of discomfort or prejudice from the dental staff, and more extreme enactments of stigma such as refusal of care. However, what mainly hindered our participants' access to dental care was the stigma they anticipated or expected to encounter. Hearing stories of other PLHIV's negative encounters with dentists and their negative experiences in other healthcare sectors could particularly induce anticipation of stigma at the dental clinic. PLHIV may try to avoid stigma either by not disclosing their status, which helps them pass as someone without HIV, or by staying in HIV networks and seeking care from dentists who openly accept PLHIV. However, they might feel that such strategies could limit their options (being able to choose only certain trusted dentists) and advantages (such as the dentist providing optimal care specific to the needs of PLHIV for those who choose to disclose) in receiving dental care. Stigma in dental care is a social problem, and dental care is just another system where HIV stigma is practiced in our society. Addressing stigma in dental settings is not achievable without addressing the inequalities in a society that allows for stigmatization to occur. The dentists who wish to change HIV stigma should not only be careful not to practice stigmatization, they should use their relevant position of power in the society to challenge social injustice.

Concluding Remarks

While listening to the narratives of our participants and reading phenomenological texts on stigma or suffering, I realized that although I never had a serious physical condition nor belonged to a stigmatized minority in the society, many of the stories and experiences of the participants resonated with me. The essential meanings of our participants' experiences are common to many human experiences and could be relatable to all of us despite our dissimilar life circumstances. Suffering is a normal and necessary part of humanness (128) that we have all experienced. Although no one can feel the suffering of another person, I believe that by understanding our own suffering we can develop an understanding for the suffering of others, which is necessary for having true compassion and empathy that a healthcare provider needs to have. Furthermore, sociologists suggest that anyone is a potential member of one or more outsider groups and likely to be stigmatized (144). In other words, we are all stigmatized in one sense or another. Possibly like our participants, all of us carry a mark, perhaps a piece of information about ourselves, that if revealed would expose us to feeling abnormal, judged, and uncomfortable in the presence of others. Reflecting on the fundamental similarity in human experiences is how we can empathize with each other, and gain a more intuitive understanding of the experiences of others. I invite dentists, including myself, to improve their philosophical and reflective skills alongside their technical expertise and scientific knowledge; to be mindful of and reflect on how the patients who are in difficult life situations, including but not limited to PLHIV, experience their illnesses. I call for a reflective and thoughtful practice of dentistry that engages with the communities and is concerned about the harsh realities and inequalities of the society.

I am going to bring this Master's thesis to an end, having addressed our research objectives. However this thesis is hopefully only the beginning of a project. We hope to use our findings for developing a workshop for dental students at McGill. We will also present our work to HIV communities in Montreal, and with the assistance and guidance of our research partners, we will use our findings to provide better support for the dental needs of their community members. We hope to take one step forward towards providing PLHIV with the best dental care possible and to ultimately improve their oral health and quality of life.

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APPENDICES

Appendix A: Consent Form

Faculty of Dentistry

McGill University,
2001 Ave McGill College,
Montreal, QC H3A 1G1

April 2016

Title of Research:

Dental care for people living with HIV, a phenomenological approach.

Researchers:

Principal investigators: Dr. Christophe Bedos. Student investigator: Mehrnoosh Alborzi. McGill University, Faculty of Dentistry, Department of Oral Health and Society.
Co-researchers: Liz Lacharpagne, COCQ-SIDA (Coalition des organismes communautaires québécois de lutte contre le sida). Daniel Lanouette, ACCM (AIDS Community Care Montreal).

Introduction:

You are invited to take part in a research study. Before you decide to take part in this study, take some time to review the information in this consent, which describes the purpose of this study and what you will be asked to do. If you have any questions about the information in this form or need additional clarification, please discuss the study with one of the researchers. You may also want to discuss your participation choice with your friends and family. Participation in this study is voluntary. It is your decision whether or not you take part in this study. If you decide to take part in this study, you can withdraw your consent at any time. If you decide to take part in this study, you will be asked to sign this consent form. You will receive a copy of this consent form to keep.

Purpose of the Research:

The purpose of this study is to explore the experiences of people living with HIV/AIDS in Montreal and their access to dental care.

Study procedures:

Your participation is completely voluntary. If you agree to take part in this study, you will be asked to take part in an individual interview with Ms. Mehrnoosh Alborzi. The interview will take around an hour and a half to complete, and will be scheduled at a time convenient for you. The interviews will either take place in a quiet room at the ACCM, or at the Faculty of Dentistry, McGill University. The interview will ask questions about your experiences with dental care access and oral health, as well as when you were first diagnosed with HIV/AIDS and medications. The interviews will be digitally audio-recorded with your permission. If you opt out of the recording, you can still take part in the study. In this case, the interviewer will document the interview with hand-written notes. The recordings will be transcribed by the same person who conducts the interviews (Mehrnoosh Alborzi). A copy of the transcript will be sent to you so that you have the opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. You have the choice to stop the interview at any time or take a break if needed. You can also refuse to answer any question asked by the interviewer. Furthermore, you may decide to withdraw from this study at any time without any negative consequences.

Possible risks:

There is little expected discomfort or risk involved in the interview mainly because it is simply to talk with a researcher. However, some of the questions or discussions during the interview may cause you discomfort or emotional upset.

Possible benefits:

You may or may not benefit from your participation in this study. The researchers hope that the information learned from this study will provide greater insight into access to dental care for people living with HIV/AIDS.

Confidentiality:

All information you provide –including your identifying data, your health information, and the responses you give during the interview- is considered completely confidential. This pledge of confidentiality means that the interview materials will be coded and stored in such a way as to make it impossible to identify them directly with any individual. The typed material will not contain any names. All the identifiable data will be stored on Mehrnoosh Alborzi's laptop, in a password-secured folder and will be destroyed after one year. Audio recordings and transcriptions with pseudonyms will be saved on the computer of Dr Christophe Bedos into a password-protected folder for seven years as per University policy, and destroyed after that. Any printed material including consent forms will be stored in a locked filing cabinet in a secure central location accessible only to the principal investigator. The findings of this study will be published in a thesis, as well as in scientific journals. You might be quoted in these; however, we will make sure that these quotations will be anonymous. All names will be erased; the readers will not be able to identify anyone- whether it is you or the people that you may mention during the interview. A representative of the McGill Institutional Review Board, or a person designated by this Board, may access the study data to verify the ethical conduct of this study.

Compensation:

You will not receive compensation for taking part in the study.

Contact Information:*

Mehrnoosh Alborzi: Student, McGill University, Faculty of Dentistry, 2001 Ave McGill College, Montreal, QC H3A 1G1. Tele: (514) 929-2184. Email: mehrnoosh.alborzi@mail.mcgill.ca

Christophe Bedos: Associate professor, McGill University, Faculty of Dentistry, 2001 Ave McGill College, Montreal, QC H3A 1G1. Email: christophe.bedos1@mcgill.ca

Liz Lacharpagne: Lawyer, Coordinator - Human Rights and HIV/AIDS Program, COCQ-SIDA. Email: liz.lacharpagne@cocqsida.com

Daniel Lanouette: Coordinator of Group Services, ACCM. Email: groups@accmontreal.org

*If you have any questions about this research study, please contact Mehrnoosh Alborzi.
*If you have any questions or concerns regarding your rights or welfare as a participant in this study, you can contact Ms. Ilde Lepore, Ethics Office for the McGill Institutional Review Board, McGill University, Faculty of Medicine, McIntyre Building, #633 – 3655 Promenade Sir William Osler, Montreal, QC H3G 1Y6. Tele: (514) 398-8302. Email: ilde.lepore@mcgill.ca

CONSENT

I agree to be interviewed ☐ YES ☐ NO

I agree to be recorded ☐ YES ☐ NO

I have read the information in this consent form. I am aware of the purpose of this study and what I am asked to do. I have asked my questions, and my questions have been answered. I was given enough time to make a decision. I am free to withdraw from this study at any time. I was informed that my name will not appear on any publications associated with this study. I do not give up any of my legal rights by signing this consent form. I will be given a copy of this signed consent form.

Name of the participant:…………………………………………… Date: ………………………

Signature of the participant:……………………………….………..

Name of the researcher:…………………………………………… Date: ………………………

Signature of the researcher:…………………………….…………

Appendix B: Interview Guide.

1- Introduction
  a. Can you tell me a little bit about yourself?
    i. What is your original language?
    ii. Where do you live?
    iii. Can you tell me about your link with the group (if part of the ACCM)?
2- Living with HIV
  a. HIV status
    i. When did you first get diagnosed with HIV?
    ii. How is your general health now?
    iii. Are you on medication?
  b. The experience of living with HIV
    i. Could you tell me about your life with HIV/ what does it mean to live with HIV?
      1. How did HIV affect your life?
3- HIV and Oral health
  a. Could you tell me about your oral health??
    i. How did your oral health affect your life?
    ii. Probe: Did HIV affect your oral health? If so how?
  b. Could you talk to me about your experience engaging with staff in dental offices?
    i. Probe: Can you describe to me your last visit to the dentist's?
    ii. How was your experience before being diagnosed with HIV?
    iii. Do you disclose your HIV status?
      1. Why?
      2. How do you feel about disclosing?
  c. Can you think of a situation in which you wished you were treated differently? Please describe the situation.
    i. To what extent you think it was because of your HIV?
      1. What were the other reasons in your opinion?
    ii. Did that situation affect you? If yes how?
    iii. How do you wish you were treated instead?
    (Examples of probing questions: experience of being discriminated against, being treated differently, or feeling uncomfortable at the dentist's)
  d. Can you remember any experiences or stories you have heard from other people living with HIV trying to access dental care? If yes please describe what you heard.
    i. How did that affect you?
  e. In your opinion how do dental professionals think about people with HIV?
    i. What are the reasons in your opinion?

    f. How were your experiences with dental staff similar to or different than other health care professionals?
4- The ideal dental setting
    a. Can you think of a good experience when trying to access dental care? If yes please describe.
        i. How did that affect you?
    b. In your experience who was the best dentist? Why? Describe the things he did differently.
    c. How would an ideal visit to the dentist's be for you?
        i. What would be an ideal dentist for you?
    d. What could be changed in dental settings in your opinion (to make you feel more comfortable)?
5- HIV related stigma in general
    a. Are there particular situations you faced in which you felt being discriminated against because of HIV?
        i. If yes would you please describe that situation?
        ii. How did this affect you and your life?
6- Do you have any comments or questions?
7- How did you find the experience of the interview?
8- Socio-demographic questions
    a. How old are you?
    b. What is your marital status? Do you have kids?
    c. Are you currently working? If yes, what is your job?
    d. What is your highest level of education?
    e. Do you have dental insurance?

Appendix C: Figure 1. An overview of the findings.