STIGMA OF ADDICTION AND MENTAL HEALTH IN DENTAL SETTINGS: PATIENTS’ EXPERIENCES

by

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ABSTRACT

Objectives: The objective of this study was to explore the nature of stigma experienced by dental patients who have substance use and mental health issues.

Methods: Semi-structured interviews were conducted with a purposefully selected group of 13 English-speaking participants (7 males) who struggled with a variety of substance use and/or mental disorders, and lived in one of two treatment centres. An interview guide containing open-ended questions was used to discuss their experiences with dental professionals, and their perceptions of stigmatization. All interviews were audio-recorded, transcribed verbatim and analyzed using a qualitative thematic analysis.

Results: Analysis of about 300 pages of interview transcripts demonstrated that participants perceived stigma in dental settings when they were viewed as “junkie” or “crazy”, were negatively stereotyped, and finally were rejected as patients or received negative attitude and substandard care from dentists who were misusing their position of power. Lack of or poor understanding and education about issues of addiction and mental health were pointed out as the origin of stigma. Positive experiences with dental professionals were characterized by empathy, reassurance and communication, which were empowering for patients.

Conclusion: Individuals with substance dependence and mental health issues felt stigmatized by some dental professionals who they felt had labelled, stereotyped, and discriminated against them; making them feel disempowered. Findings of the study highlighted the need to better prepare current and future dentists to address the oral care of patients with substance dependence and mental illness in their clinical practice.
PREFACE

Ethics approval for the present study was obtained from University of British Columbia’s Behavioural Research Ethics Board (BREB#: H12-03176).

Dr. Mario Brondani was the supervisor of my research project. Under his supervision, I conducted interviews, thematically analyzed the interview data, and prepared this thesis.
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<table>
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<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>AA</td>
<td>Alcoholic Anonymous</td>
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<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
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<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>BREB</td>
<td>Behavioural Research Ethics Boards</td>
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<td>BCMHA</td>
<td>Burnaby Centre for Mental Health and Addiction</td>
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<td>CAS</td>
<td>Canadian Addiction Survey</td>
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<td>CSL</td>
<td>Community Service Learning</td>
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<td>DMD</td>
<td>Doctor of Dental Medicine</td>
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<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<td>LSD</td>
<td>Lysergic acid diethylamide</td>
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<td>MMT</td>
<td>Methadone Maintenance Therapy</td>
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<tr>
<td>MSc</td>
<td>Master of Science</td>
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<td>NHS</td>
<td>National Health Services</td>
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<td>OCD</td>
<td>Obsessive Compulsive Disorder</td>
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<td>PACS</td>
<td>Professionalism and Community Service</td>
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<td>PCLA</td>
<td>Pioneer Community Living Association</td>
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<td>PLWHA</td>
<td>People Living With HIV/AIDS</td>
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<td>PTSD</td>
<td>Post Traumatic Stress Disorder</td>
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<td>University of British Columbia</td>
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<td>WHO</td>
<td>World Health Organization</td>
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ACKNOWLEDGMENTS

I would like to express my gratitude to my supervisor Dr. Mario Brondani for his continuous encouragement and guidance. I learnt from his expertise, ethics, enthusiasm, and patience, and because of his mentorship, my graduate experience was more enjoyable than I had ever imagined being.

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I must acknowledge my mom and dad whose careers and professional ethics inspired me to do this research, as well as my older brother, Nima, who along with my parents supported me through my entire life.

Last but not least, I greatly appreciate all my participants for sharing with me their sensitive life stories.
DEDICATION

I dedicate my work to all those people affected by addiction and mental illness and to scholars and health professionals who serve them.
CHAPTER 1: INTRODUCTION

1.1 Background

In May 2000, Surgeon General Dr. David Satcher released the landmark report *Oral Health in America*, the first ever to focus on oral health. This report acknowledged that despite a significant improvement in the overall level of oral health among Americans in the past 50 years, certain groups still experience limited or no access to oral care.¹ In the thesis that follows, I draw attention to one of these disadvantaged groups: those with history of addiction and mental health.

Majority of Canadians drink alcohol and close to half of them have used at least one other substance (such as cannabis, hallucinogens, cocaine, amphetamines, ecstasy, heroin, steroids, LSD, and inhalants) during their lifetime, subjecting themselves to a great risk for developing addiction.² In addition a recent survey has shown that in Canada 16% of people who do develop substance dependence also have co-occurring mental illnesses.³ One of the difficulties these individuals face is the stigma from the society at large and from health providers in particular. I designed my research to explore the stigma that a population of patients affected by addiction and mental health problems encounter when interacting with dental professionals. I have structured my thesis as follows: I start by describing my systematic review to set the stage to explain the concept of stigma, its relation to addiction and mental illness, and how it negatively affects the quality of life individuals. Next, I argue that quality of health care services stigmatized individuals receive especially those with problematic substance use and mental health issues is perceived to be often compromised. I then propose my study’s research question...
and objectives, followed by the methods I chose to address them, and the way in which I analysed the information collected. Finally, I proceed to present and discuss my findings while drawing from the existing literature, and concluding with the implications and limitations of my research.

1.2 Narrative Search

I employed a narrative search strategy to gather relevant information about stigma of addiction and mental health in dental settings. Various combinations of key words “stigma”, “dent*”, “addict*”, and “alcohol*” were used to search through the PubMed database1 (Figure 1). I limited my search to studies involving human subjects, with full texts available, and in the English language.

Figure 1 shows the several steps taken to complete this systematic search. Using the terms from the top row of Figure 1 I performed four separate searches. I then carefully examined the titles from each search result and eliminated those which I judged as clearly irrelevant to the topic of my study, e.g., those about smoking cessation or drug detoxifications programs. Next, in a word document I listed all titles I had identified as useful. This step allowed me to compile all the articles (N=112) I had included solely based on their titles, and to eliminate duplicates (N=9) which were retrieved from more than one search. Further, I read the abstract of the remaining 112 papers after which I eliminated 67 more as they were for example focusing on the medical model of addiction, or exploring addiction amongst dental professionals. In addition to my electronic search, I also found 17 publications by hand searching the reference lists of the already retrieved

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1 Adding “mental” to my search terms excluded too many of the useful publications, and using “prejudice” instead of “discrimin*” or “stereotype” gave similar results.
articles. In total, I collected 62 relevant manuscripts which I read and used throughout my thesis. Appendix A provides a complete list of these manuscripts.

Figure 1. The step-by-step process of narrative literature search

1.3 What is Stigma?

The term “stigma” originates from ancient Greece, referring to a symbol that was cut or burnt into mostly slaves’ and criminals’ flesh to show their moral deficiency and that they should be avoided by others. Today, stigma is used frequently in the literature,
yet its definition is often imprecise and ambiguous, and there seems to be little consensus on what the concept of stigma exactly is. For example, while some refer to it as its dictionary definition, *a mark of disgrace*;5 others use it interchangeably with terms such as *discrimination, prejudice* and *stereotyping*.6 It is suggested that because of the complexity of the concept of stigma, it is reasonable to allow for variation in definitions, as long as authors provide sufficient clarity on what they mean by stigma within the context they are using it.6

Erving Goffman, a very influential American sociologist, was the first who attempted to understand stigma and explore the social process of stigmatization more fully.7 In his wildly read and frequently cited book, *Stigma: Notes on the management of spoiled identity*, he defined stigma as a deeply discrediting attribute which is the source of social disqualification.4 His work was mainly based on autobiographies and case studies of mental patients, ethnic minorities, the disabled, and those with facial deformities; all of whom he believed “*disqualified from full social acceptance*”(p.126).7

Goffman’s work was the start of modern perspectives on studying stigma, and since then, there have been several attempts to conceptualize it. Below I discuss two of the current conceptualizations of stigma.

**1.3.1 Thornicroft et al.’s conceptualization**

One of the contemporary ways of conceptualizing stigma is to describe it as a combination of ignorance, prejudice and discrimination, which respectively correspond to deficits in knowledge, attitude and behaviour. The seemingly similar terms attitude and behaviour refer to different concepts: attitude is related to emotions while behaviour is how people act or what they do. According to Thornicroft et al., lack of knowledge about
certain conditions leads people to experience stress-related responses and feelings when encountering individuals who have those conditions. Such negative emotions can result in formation of negative attitudes, which then lead to rejection, avoidance and other forms of discriminatory behaviours.\textsuperscript{8} It must be mentioned that Thornicroft et al.’s description of stigma has been used by other researchers, but only in relation to mental disorders.\textsuperscript{9,10} Even though this conceptualization suggests that interventions such as improving public knowledge and enforcing anti-discrimination laws can reduce stigmatization, it entirely excludes any discussion of why stigma persists.\textsuperscript{10}

\textbf{1.3.2 Link & Phelan’s conceptualization}

Link and Phelan have suggested that stigma comes to existence when five intertwined components occur together: labelling, stereotyping, social exclusion, discrimination and power relations.\textsuperscript{6} Labelling happens when people recognize human differences and categorize individuals into groups based on those differences. Labelled individuals are then associated with negative characteristics as they are stereotyped. Next, social exclusion or separation of labelled and stereotyped individuals from the rest of the society occurs (i.e., “them” vs. “us”). The fourth component involves diminishing the social status of these individuals by behaving toward them in discriminatory ways. While the four aforementioned components are necessary for development of stigma, exercise of power remains vital for that to happen.\textsuperscript{6} In other words, weak groups are not able to stigmatize powerful individuals although they may engage in stigma-related processes (e.g., labelling, stereotyping, social separation, and discrimination). For instance, in a mental hospital, nurses (i.e., at higher power) do not become stigmatized even though
patients (i.e., at lower power) may label them “pill pushers”, stereotype them as being “cruel”, or even treat them negatively.\textsuperscript{6}

Power is essentially exercised as a way to control and influence groups, and may fluctuate depending on the context in which it is observed. The nature of power relations may vary from social, economic or political, but every interaction is influenced by these relations.\textsuperscript{11} Figure 2 is the visual model which I designed based on my interpretation of Link and Phelan’s conceptualization of stigma. It depicts the four components of stigma overlapping with each other while emphasizing that power influences all of these components.

\textbf{Figure 2. Visual model of stigma}

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\includegraphics[width=\textwidth]{figure2.png}
\end{figure}

I have chosen Link and Phelan’s conceptualization of stigma and my graphic presentation of it as the framework for my research. This conceptualization, unlike
Thornicroft et al.’s, has been applied to studies on several stigmatizing conditions such as abortion, HIV, and homosexuality, in addition to mental illness.\textsuperscript{12,13} It expands on Thornicroft et al.’s ignorance, prejudice and discrimination by acknowledging the role of power in both development of stigma, and difficulty of extinguishing the already-established stigmas. Moreover, Link and Phelan’s conceptualization thoroughly describes the process of discrimination as a mechanism that can manifest itself on both individual and structural levels. When a negative treatment such as refusing to hire someone with a stigmatizing condition happens, it is considered individual discrimination. The harder to discontinue and yet more prevalent type of discrimination is the structural one which occurs when high power groups (or institutions) create situations that are disadvantaging to certain groups, e.g., when government allocates less funding to research on mental illness compared to physical diseases.\textsuperscript{6}

While both conceptualizations discussed above capture the social aspect of stigma, it must be pointed out that stigma can be directed towards the ‘self’ as well. Social stigma, also known as external, public, or enacted stigma, is believed to be widely held by the general population. It entails forming negative beliefs about certain groups (i.e., stereotype), feeling negatively towards them (i.e., prejudice), and showing the detrimental beliefs and emotions through actions (i.e., discrimination).\textsuperscript{14} In the case of mentally ill individuals, for instance, the general public may view them as dangerous, express fear towards them, and consequently withhold employment or housing opportunities.\textsuperscript{15}

On the contrary, self or internal stigma is the stigma against the ‘self’, usually as a result of public stigma within a heavily stigmatizing society.\textsuperscript{14} A person with physical disability who is stigmatized by the public may believe for example that s/he is
incompetent and demonstrate lower self-efficacy and hence may fail to pursue a work opportunity.  

15 Because self-stigma is usually a product of public stigma, reducing stigmatization at the societal level can reduce self-stigmas. Therefore, throughout my research I only examine social stigma, and use the general term stigma to refer to the ‘social’ one.

1.4 Impact of Stigma

1.4.1 Stigma and quality of life

Those with stigmatizing conditions usually experience disadvantages in some of the basic standards of living including financial, work and housing opportunities, which can negatively influence their quality of life.  

16 Studies have shown that compared to the general population, stigmatized individuals report poorer quality of life especially in areas of social relationships and psychological well-being.  

17 This population also may become excluded by the general public and even family members from most social activities. Such social distance and lack of social support can result in a wide range of psychological problems including depression and anxiety as well as diminished self-esteem and self-efficacy.  

18 However, studies have shown that reduction in self-esteem only occurs when stigmatized individuals believe that they deserve the stigmatizing actions that are directed toward them. On the other hand, when the stigmatized individual does not legitimize the negative actions of others, self-esteem is not damaged although feelings of anger and indifference may surface.  

18 Nevertheless, the emotional discomfort

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II According to Health Promotion Glossary of World Health Organization (1998), Quality of Life is “individual’s perceptions of their position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way a person’s physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment.”
from being stigmatized is inevitable to the extent that in the long term, stigma can change the person’s self-concept in such a way that s/he does not identify his/her own positive characteristics and capabilities.\textsuperscript{19}

\textbf{1.4.2 Stigma in the health care}

Another impact of stigma, which is of special interest to me, is on the quality of health care services. Even though a large proportion of health care providers attend educational sessions on stigma and discrimination, studies show that most health providers are not very different from the rest of society in holding stigmas against certain populations.\textsuperscript{20} Such stigma is manifested in a wide range of behaviours, from refusal of care\textsuperscript{21} to unethical treatments and expressions of discomfort around patients.\textsuperscript{20} The above behaviours disrupt patient-provider rapport and more importantly, cause delay or avoidance of treatment in many cases.\textsuperscript{22} It therefore becomes important to address health workers’ stigmatizing attitudes because of the negative impact on patients’ care-seeking patterns.

Despite the efforts put forward at undergraduate and continued educational levels,\textsuperscript{23} lack of awareness is still to a great degree responsible for the stigmatizing attitudes of health professionals.\textsuperscript{20} Even more disturbing is that some health care providers are taught to keep social distance from their patients in order to avoid getting distressed or making emotional decisions about treatments, which further increases stigma.\textsuperscript{21} In particular, the stigma associated with mental illness and addiction that prevails in our society and amongst health providers was the focus of my study.
1.5 Addiction and Mental Health

Addiction is defined as “a disease that is characterized by behaviours that include impaired control over drug use, compulsive use, continued use despite harm and craving or a combination of these”\(^2\text{4}\) (p. 801). I use the term “addiction” interchangeably with ‘drug/substance dependence’. While for some there is a distinction between drug use and abuse, I use both terms to refer to “use of an illegal drug or self-administration of a medication for non-medical purposes” (p.801).\(^2\text{4}\)

In order to understand the stigma around addiction, I applied Link and Phelan’s\(^6\) conceptualization discussed above (Figure 2) as follows: labelling refers to marking the dependence on substances as a human difference for those who have a compulsive need to use drugs; stereotyping implies linking the addict to undesirable traits such as being irresponsible, manipulative, immoral or untrustworthy; next, exclusion comes when society, family, and friends separate themselves from the user; and lastly the user experiences discrimination and status loss with legal, financial, medical and job-related issues.\(^2\text{5,26}\) Stigma of addiction is formed through the influence of societal power structures as society as a whole considers substance dependence, and its related behaviours, morally unacceptable.\(^2\) With legal drugs, such as alcohol and cannabis (in some parts of the world), the role of power can perhaps be traced back to attempts to control and minimize hazardous use of these drugs.\(^2\text{7}\) With illicit drugs, in addition to these social powers, the federal power is at work also. Government regulations on the dispensing of certain drugs direct the society towards associating negative characteristics to users of these drugs such as thinking of them as immoral criminals. In fact, anti-drug
policies have caused some users to become involved with violent crimes and prostitution through their drug dealers, thus confirming the society’s negative attributions.\textsuperscript{26}

Stigma of addiction is extremely complicated as drug dependency is closely intertwined with mental illness. In fact, a US National Comorbidity Survey demonstrated a 50\% co-occurrence rate between the two.\textsuperscript{26} Similarly, a study completed by the Comorbidity of Substance Misuse and Mental Illness Collaborative team in the UK also found that nearly half of people with a mental disorder have co-occurring substance use issues.\textsuperscript{28} Some of the common mental disorders that happen simultaneously with addiction are major depression, general anxiety, bipolar disorder and schizophrenia.\textsuperscript{26}

In an attempt to understand the temporal relationship between addictive and mental disorders, some longitudinal studies have reported that a past history of mental illness increases the risk of future substance dependence considerably.\textsuperscript{26,27} Based on these findings, some researchers suggest that mental illness is the primary disorder which is followed by a secondary addictive disorder.\textsuperscript{29} However, there also exists opposing evidence, showing that long-term and high intensity use of substances can diminish psychological development and mental health status.\textsuperscript{30} Therefore, even though addiction and mental disorders strongly correlate, there is no proven causal relationship between the two as the direction of the link seems to vary on an individual basis.\textsuperscript{27}

Furthermore, it is worth mentioning that many experts in psychiatry suggest that since addiction/alcoholism is a behaviour-related condition, it could be classified as a mental illness.\textsuperscript{31} In fact, “Substance-Related and Addictive Disorders” continues to exist as a group of mental health disorders in the most recent edition of Diagnostic and Statistical Manual of Mental Disorders, which was published by the American
Psychiatric Association in 2013. Interestingly, surveys from United States and New Zealand showed that less than half of the general population recognized substance dependence as a mental illness. In my thesis, for the purpose of clarity, “mental illness/disorder” refers to other mental health issues including but not limited to depression, bipolar disorder, general anxiety disorder, mood disorder, schizophrenia, and post-traumatic stress disorder.

Since addiction and mental health seem to be closely related, the issue of stigma against these co-occurring conditions must be addressed. Mental illness alone is a stigmatizing problem as numerous studies have all found that, in a variety of cultures and amongst various social gradients, individuals who are diagnosed as mentally ill and/or use mental health services experience stigma. For instance, a study looking at the general public’s opinion about mental health showed that development of mental illness is largely thought to be due to a weakness of character and the patient is blamed for becoming mentally ill. Although this is perhaps not near the level of the blame and judgment that addicts normally receive, mental illness remains a major stigmatizing condition. More importantly, the two conditions together lead to a “dual stigma” which effects can potentially be larger than the sum of the effects of each. Particularly, these individuals are **doubly vulnerable** to not receiving quality health care services.

Stigmatizing attitudes extend their reach to health providers. Studies show that health providers view patients with substance use and mental health disorders as being manipulative, demanding, and generally ‘difficult’. Given that addiction and mental illness are health-related stigmas, the role of health professionals becomes more prominent than in other types of stigma. It is known that drug users are at risk for
numerous health conditions including, but not limited to, heart disease, high blood pressure, cancer, and sexually transmitted infections such as HIV/AIDS. However, the shame and fear of being stigmatized drives those with addiction away from appropriate health services unless they face an emergency.\textsuperscript{22} This is significant because postponement of treatments not only deteriorates the person’s well-being further but also leads to increase in the costs to the health care system.\textsuperscript{26} Although feelings of shame and fear can be present in all vulnerable populations, they are magnified in patients with substance dependence and mental illness since they may need to share details of the stigmatizing condition (e.g., drug of choice, drug’s route of entry, and so on) with their health provider.\textsuperscript{26}

Oral diseases are also very prevalent among drug users when compared to non-drug users. For example, drug users more than non-users are likely to report that in the past year they experienced toothache, cavity, tooth/filling loss, grinding teeth, or bleeding gums.\textsuperscript{38} Some of these problems could be explained in part by their improper oral hygiene and poor nutrition such as cravings for a sugary diet and low fibre intake. Such unbalanced diet along with neglect of oral hygiene can increase the risks for gum inflammation and tooth decay.

Despite such problems, the substance users tend to access dental services less frequently than the rest of the population.\textsuperscript{39} In fact, a study by Charnock et al. which explored dental attendance of addicts found that while the majority of them had teeth/mouth problems, 25\% of them had never visited a dentist and almost half of them only visited one when in pain.\textsuperscript{40} While underuse of dental services might be due to low priority of oral health, low/unstable income and disorganized lifestyle, the co-occurrence
of mental disorders with substance dependence leads to high levels of dental anxiety, which also discourage users from seeking dental care.\textsuperscript{39} Furthermore, the stigma received from dental professionals might also be an important contributing factor since as many as 50\% of the drug users in Charnock et al. study reported unsympathetic attitude of dentists as a reason for not using dental services.\textsuperscript{40}

Also, Sheridan et al.\textsuperscript{38} in their study of accessibility of dental care for drug users in the UK, found that being refused by dentists made patients feel stigmatized. The authors also discussed that dentists felt uncomfortable treating substance users, regardless of their mental condition, and made excuses such as being too busy, or not having appointments available. Again, even those patients who had not experienced difficulty accessing dental care seemed to utilise services less often, and stigmatization from dental professionals seemed to be a barrier. That study is the only one available in the literature that looked at the experiences of individuals with substance dependence in dental settings from the perspective of patients. However, they used a questionnaire with close-ended questions which limited patients’ responses, and did not allow for collection of rich data that could have better explored the topic. In fact, the findings mostly focused on how stigmatization may affect accessibility of dental treatment to users, but not how patients perceive stigma from dental professionals or how they feel about their experiences in dental settings. It also did not explore the co-occurrence of mental disorders with substance dependence and how dental professionals may stigmatize patients with both these conditions.\textsuperscript{38} For this reason, a qualitative research is suggested to explore this issue further.

Qualitative research is a methodological approach aimed to obtain an understanding of people’s social circumstances and experiences. It explores questions of “what”, “why”
and “how” of these circumstances, and emphasizes the way phenomena are perceived by those who have experienced or are experiencing them.\textsuperscript{41} Researchers utilise qualitative research to find an insight to a complex phenomenon which is intertwined with social and psychological factors. In other words, qualitative methodology gives researchers the opportunity to study subjects which could not be adequately addressed by quantitative methods.\textsuperscript{42} Compared to quantitative studies, findings of qualitative research are non-numeric, in-depth and detailed, and generate information which uncovers the meanings and feelings that participants attach to their experiences. In particular, a qualitative study that includes interviews with open-ended questions can lead to very rich findings as it allows the researchers to understand the perspective of respondents by listening to their stories.\textsuperscript{43}

Research findings on the stigma of addiction & mental illness in dental settings are still very limited, and no qualitative study has examined this subject from the viewpoint of the stigmatized. Therefore, the purpose of my study was to conduct personal in-depth interviews by means of open-ended questions to explore the stigmatizing attitudes and behaviours that patients with a history of substance dependence and mental illness may perceive and experience when accessing and receiving dental care. In particular, I attempted to answer the following research question: \textbf{How do individuals with addiction and mental health issues experience stigmatizing behaviours from dental professionals?}
1.6 Objectives

In order to address my research question, I set following specific objectives for my study:

1) To determine whether individuals dealing with substance abuse and mental illness experience stigma/feel stigmatized in dental settings.

2) To identify the nature of the stigma this population perceives from dental professionals.
CHAPTER 2: METHODOLOGY

My approach to this research was based on the idea that every participant had constructed his or her own “reality”, and that each of those realities were valid and worthy of understanding. This is essentially the main concept in the paradigm of constructivism. Each participant had unique experiences with dental professionals which as the researcher, I was interested in understanding. My interviews were learning experiences between me and my participants. I believe that our interactions refined the way I understood dentists’ relationships with patients who had substance use and mental disorders. Some of the participants also seemed to have gained a better insight into their own experiences and the meaning of those experiences as they spoke them.

Qualitative description is the common method used to subjectively describe the perceptions and experiences of participants without being highly interpretive. In my study, I adopted this method while integrating some aspects of phenomenology and grounded theory. My approach had phenomenological overtones since I was studying the nature of the phenomenon of stigma through exploring how it was perceived by patients who were affected by substance use and the mental disorders. The aim was to better understand what it is like for these individuals to experience stigma in dental settings. That being said, I focused on describing the meanings of participants’ experiences and feelings but did not bring the level of depth and interpretation of the essence of that phenomenon that is typically present in pure phenomenological studies. I also did not bracket and put aside my own perceptions of participants’ experiences as a pure phenomenological researcher might. In addition, there existed some aspects of grounded theory: my attempt to recognize the specific components of stigmatization
among dental professionals\textsuperscript{43} followed by development of a model of addiction and mental health stigma in dental settings.\textsuperscript{48} This is essentially what Creswell referred to as “an abstract schema of a phenomenon that relates to a particular situation”.\textsuperscript{45}

My personal stance and sensibility to the topic influenced the process of describing events and how the final description was shaped. The main goal however remained to present a comprehensive and straightforward description of the factual content of the interviews and their meanings from the viewpoint of my participants.\textsuperscript{46} Overall, by employing a qualitative descriptive approach with hues of phenomenology and grounded theory, my study explored the stigma in dental settings directly from the perspective of substance users with mental illness.

\section*{2.1 Sampling and Data Collection}

As in most qualitative studies, purposive and convenient sampling was used to select participants.\textsuperscript{45} They could be individuals of any gender, age, sexual orientation, ethnicity and educational background who were diagnosed with one or more type of mental illness and had dependence on one or more substance. Moreover, given that I was interested in understanding experiences of drug users with dental professionals, I required that my participants had visited a dental clinic since the development of their addiction and/or mental illness.

Prior to proceeding to data collection, approval for this research was obtained from Behavioural Research Ethics Board (BREB) at University of British Columbia. Burnaby Centre for Mental Health and Addiction (BCMHA)\textsuperscript{49} was suggested as a recruitment site by its former director and a member of my MSc committee, Dr. Michael Krausz. This is a long-term residential treatment centre which provides services for those with combined
addiction and mental health issues thus every client at this centre qualified to participate in my study.

My recruitment strategy included posters (Appendix B) on the bulletin boards of the Burnaby Centre, clearly stating the eligibility criteria for participation. Initial contact with the participants was made through the volunteer coordinator, and the organizer of the incentive program at BCMHA. This indirect approach was beneficial as it allowed me to reach my targeted population which had limited access to email or phone. Therefore, the recruitment poster referred potential participants to my contact person at BCMHA for more information. They could ask questions about the study, review the informed consent (Appendix C), and address any possible concerns. My contact person kept a weekly list of clients who were interested and on my regular visits to the centre I reached these clients personally and asked them for a time that was convenient to them. In most cases, they wished to be interviewed immediately, some however asked for a later day/time which I accommodated into my schedule. All interviews were held in private spaces at the BCMHA where the participants resided at the time of the interview.

My goal was to interview enough participants to reach some saturation, e.g., a point in which no new information emerges and the content becomes repetitive as data is analyzed. Due to the exploratory nature of my study, I had foreseen that between 10 and 15 interviews will suffice to address my objectives and research question. In fact, after conducting 11 interviews, the information had become repetitive. That being said, since recent experiences of the majority of participants at the Burnaby Centre were with the same dentist, whom the clients were referred to by the centre, it was decided to recruit from other locations.
One participant was recruited through word-of-mouth. After hearing about this research, he expressed interest in sharing his experiences as someone who had been diagnosed with a mental illness. I then personally contacted this potential participant through email to better inform him about the purpose of the study, the consent form, and the interview process. Afterwards, a time and location of convenience to the participant was arranged for the interview.

In addition, Pioneer Community Living Association (PCLA)\textsuperscript{51} was suggested as a potential recruitment site by Dr. Leeann Donnelly, another member of my MSc committee, who organizes UBC dental hygiene services at this site. PCLA is a non-profit organization which provides residential programs and affordable housing for people with a mental illness. With the help of a group of UBC dental hygiene students who provide care at the Pioneer House, I recruited one of the residents who wished to participate after hearing about the study.

It must be noted that these last two participants were disconfirming to my inclusion criteria as they only had mental illness but no addiction. Nevertheless, after the thirteenth interview, it was confirmed that saturation or data adequacy\textsuperscript{52} had been achieved\textsuperscript{iii} as patterns were seen, new information was not emerging, and I had gained sufficient information to answer my research question.\textsuperscript{45}

### 2.2 Interview Process

I started the interview by introducing myself and explaining my affiliation with UBC Dentistry. I then went over the consent form to ensure that the participant had understood and signed it. Further, participants were given a questionnaire which asked

\textsuperscript{iii} I do not however claim that I have captured all experiences about stigmatization in dental settings as that may never be obtained.
about their demographic characteristics and challenges with addiction and mental illness (Table 1). I offered to read out the questions and write down their answers if they preferred, which some of them did. Once the demographic questionnaire was completed, I turned on the digital audio recorders to record the conversations. A pre-designed interview guide (Appendix E) was used to elicit information and explore my topic. Although not a validity test as in a quantitative research, my first interview served as a pilot test to revise the interview guide questions if necessary. I incorporated the information I had collected through the demographic form to make the questions specific to each participant. In accordance with the exploratory nature of qualitative research, interview questions varied from one interview to another while covering the same topic areas. The areas of interest discussed over the interviews were participants’ perception of stigma, their experiences of stigma in the society generally and in dental settings particularly. I posed open-ended questions which provided adequate coverage of all the information relevant to my research question and objectives. I narrowed down my questions about the broad concept of stigma by drawing upon the five components from Link and Phelan’s conceptualization. In addition to asking about their personal experiences, I attempted to use a ‘collective voice’ in my questions in order for them to talk more freely about sensitive topics. For instance, I would use “people in situation similar to you” instead of saying “you” all the time. Furthermore, after each question, I gave the participant time to think about the question, and then checked whether they were clear about what I had asked. If necessary, I repeated or rephrased the question. I also encouraged participants to extend their answers and managed short responses by probing more detailed information (e.g., “can you tell me more about that?” or “why did you feel
that way?”). Throughout the interview process, I ensured my tone of voice and body language were not intimidating but welcoming, and that participants felt comfortable sharing their experiences with me. They were also told in advance that I may occasionally take a few notes as we talked. I wrote down my observations, such as participants’ emotions, which could not be preserved by voice recorders. Even though I was taking notes, the eye contact and natural flow of conversation was not disturbed as I listened to them actively and showed my attentiveness by occasionally nodding my head, making short agreeable comments such as “uh-huh”, and restating their sayings. Deviations from the interview questions were handled gently so that participants did not feel frustrated or neglected. For example, if they started talking about an unrelated topic, I did not interrupt them and let them finish their story before transitioning back to the interview questions. Once we had discussed all the topic areas, I closed the interview by giving participants a chance to tell me anything else they liked to share, and thanking them for their time. Even though the entire interview process took longer, the recorded section of interviews varied in length between 20 and 51 minutes, with an average of approximately 40 minutes. Each participant was given a $10 coffee card for their time, while donations of personal hygiene products were provided to BCMHA as well.

2.3 Data Analysis

Data analysis and data collection took place simultaneously (i.e., in a zigzag process)\textsuperscript{45}. This design allowed me to identify the strengths and drawbacks of my interviewing and modify them for the subsequent participants accordingly. Plus, the discoveries from one interview influenced the questions and probing for the next ones. For instance, in one of the early interviews a participant mentioned having intolerable
pain after dental procedures due to not being prescribed proper medications so in my subsequent interviews I posed questions regarding pain management during and after dental appointments.

Following completion of each interview, I listened to the audio-recordings and transcribed everything verbatim. Pseudonyms were used to maintain the confidentiality of participants. Even though producing the data was guided by the research question and the pre-developed interview guide, some of what was said (e.g., their family situation) during few interviews was not directly relevant to my specific research question. Therefore, I first read the raw text in detail several times, identified and highlighted sections which were pertinent to answering my research question. Next, an iterative thematic analysis was used to review the transcripts. Within the relevant data, I attached a code to each important word or phrase that participants had used. This helped me identify repeating ideas within and between transcripts which I then categorized as emerging themes. As I described earlier, the conceptualization of stigma suggested by Link and Phelan (2001) served as my theoretical framework: I attempted to group the themes under one or more of the components of stigma from this model: labelling, negative stereotyping, discrimination and power relations. These domains were present within different interactions my participants had experienced with dental professionals. As in an iterative process, I manually coded and analyzed each transcript starting from a general coding and progressing to a more refined one. Figure 3 illustrates an example of how the coding process and thematic analysis were carried out.
Figure 3. Example of coding and thematic analysis

Quote excerpt from an interview

*A lot of times they [dentists] would just pull the tooth rather than work on it, rather than do what they have to do to save it, because pulling a tooth takes very little time and doing the other work takes a lot of time so they just rip one right off instead of doing maybe you know some serious... it might need a bad filling but that would take longer than just ripping the tooth out. I’ve had 2 teeth ripped out like that!*

Identification: Codes include “substandard treatment” and “unworthiness”; themes includes “discrimination” and “stereotyping”.

Application: Repetition of the code and theme are searched when reading and analyzing other transcripts.

Research Question: How do individuals with addiction and mental health issues experience stigmatizing behaviours from dental professionals?
2.4 Rigour in My Research

The word “rigour” can be a synonym to “validity” and is defined as “being believable and trustworthy”. Rigour in qualitative research has been discussed in several ways. Some have suggested that it can actually harm the artfulness and creative nature of qualitative inquiry as researchers would have to follow a set of rules for collection and analysis of their data. On the other hand, some argue that specific criteria are essential to ensure rigour and when those criteria are not met the scientific quality of research is jeopardized. In my study, rigour is the quality of the study, referring to clarity of the process and demonstrating that there is sufficient evidence supporting all represented claims. Throughout my study, I was committed to establish this rigour and increase the quality of my study, thus persuading the reader/evaluator of my work who may be doubtful of the usefulness of the findings.

Because the topic of my research was sensitive, it was important to create rapport with potential participants prior to interviewing them. As discussed above, I chose to volunteer at the Burnaby centre where I recruited the majority of my participants. I spent approximately 60 hours in the centre over 4 months. My regular presence at the centre was not only beneficial in the recruitment process, but also in making the participants feel at ease when they talked about their experiences. Moreover, during the interview, I did not criticize or judge participants and they were welcome to talk about their experiences in as much detail as they wished, without any pressure from me. Furthermore, I personally transcribed the recorded interviews verbatim. This activity enhanced the accuracy of coding as I listened to every participant’s sayings repeatedly and paid attention to their tone of voice and emotional expressions.
It is important to acknowledge that as per any investigator in qualitative research, I brought my personal background and biases into both collecting and interpreting my study data.45 I am a healthy female with no mental or substance use disorders. These were the characteristics that participants were exposed to, and might have caused some to not share uncomfortable or embarrassing experiences. However, to minimize the effect of my biases on the coding and analysis, I had regular meetings with my supervisor, who is knowledgeable about qualitative research methods. We discussed the process of my data collection and analysis, and he thoroughly examined the complete coding which I had undertaken for my transcripts. During the iterative analyses, I took into consideration all the comments and feedback I had received from my supervisor and committee members.

In my writing, I provided evidence for my interpretations by including quotations from the participants (i.e., technique of “giving voice”).59 In addition, I wrote in first-person as a way of positioning myself in the text and showing that as the researcher I influenced the interview through my reactions to what they were saying. This matched my constructivist stance, which I described previously, and emphasised that the interactions between me and my participants were an essential part of understanding the essence of experiences.60

Unfortunately, the process of member checking, through which participants review the researcher’s interpretations of the interview data to assure they resonate with them,56 was not feasible for several reasons. It was difficult to contact with some participants again. For example, one participant from Burnaby Centre already left the site and decided not to continue with treatment while several others completed their recovery stay at BCMHA and returned to community life so I did not have access to them. In addition,
due to a history of substance use and being on medications for mental illness, most participants lacked the concentration required to go over the many pages of transcripts and my detailed interpretation of each quote. In fact, I noticed that it was frustrating and tiring for some participants to read even the consent form and short pre-interview questionnaire (Appendix D).
CHAPTER 3: RESULTS

I have organized the Results as follows. I first describe participants’ demographic characteristics which I collected through the pre-interview questionnaire (Appendix D). I then move to presenting the information derived from the interviews. I begin by explaining how my participants understood and defined stigma. Next, I discuss the five components of stigma (e.g., labelling, stereotyping, social exclusion, discrimination and power) which except for social exclusion I will refer to as domains. I then talk about the non-stigmatizing experiences of my participants with dental professionals. And lastly I highlight the interactions of the domains and the emerged themes with each other. All domains and themes are interconnected and must be understood together but for the purpose of clarity I discuss each domain individually. Examples from the interviews are provided as evidence while confidentiality is maintained by referring to participants as per Table 1. I included some experiences that participants had with health professionals other than dentists, and society in general because of the relevance they had to the phenomenon of stigma.

3.1 Participants

Details of the thirteen purposefully selected English-speaking individuals who struggled with a variety of substance use and/or mental disorders are provided in Table 1. As self-reported information, this table might contain some discrepancies if compared with medical files of participants. However, in this qualitative study, I was less concerned with the type of mental health diagnosis or the type and length of substance use, and more interested in the nature of the stigma that these individuals had perceived and experienced. For this reason, I did not look at participants’ medical files to confirm the
details of what they had reported. In fact, the interview data showed that the stigma perceived in dental settings did not vary depending on the patient’s specific condition.
<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Mental Health Diagnosis</th>
<th>Substance of Abuse</th>
<th>Addiction period (Yrs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Male</td>
<td>37</td>
<td>Depression, Anxiety, Mood Disorders</td>
<td>Alcohol</td>
<td>22</td>
</tr>
<tr>
<td>2</td>
<td>Female</td>
<td>39</td>
<td>Depression</td>
<td>Alcohol</td>
<td>20</td>
</tr>
<tr>
<td>3</td>
<td>Female</td>
<td>28</td>
<td>Depression</td>
<td>Heroin, Crack, Alcohol</td>
<td>8</td>
</tr>
<tr>
<td>4</td>
<td>Male</td>
<td>Not Disclosed</td>
<td>Obsessive Compulsive Disorder (OCD)</td>
<td>Alcohol</td>
<td>Not Disclosed</td>
</tr>
<tr>
<td>5</td>
<td>Male</td>
<td>28</td>
<td>Depression, Schizophrenia</td>
<td>Crystal Meth</td>
<td>11</td>
</tr>
<tr>
<td>6</td>
<td>Male</td>
<td>53</td>
<td>Paranoia Schizophrenia</td>
<td>Crack, Cocaine</td>
<td>20</td>
</tr>
<tr>
<td>7</td>
<td>Female</td>
<td>43</td>
<td>Bipolar Disorder</td>
<td>Cocaine</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>Female</td>
<td>41</td>
<td>Bipolar Disorder, Post-Traumatic Stress Disorder (PTSD), Depression, Anxiety, Attention Deficit Hyperactivity Disorder (ADHD)</td>
<td>Crystal Meth</td>
<td>18</td>
</tr>
<tr>
<td>9</td>
<td>Female</td>
<td>54</td>
<td>Anxiety, Depression</td>
<td>Heroin, Cocaine, Methamphetamine, Lysergic acid diethylamide (LSD)</td>
<td>10</td>
</tr>
<tr>
<td>10</td>
<td>Male</td>
<td>52</td>
<td>Bipolar Disorder</td>
<td>Cocaine</td>
<td>35</td>
</tr>
<tr>
<td>11</td>
<td>Female</td>
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<td>Depression, Anxiety, Mood Disorders, Attention Deficit Hyperactivity Disorder (ADHD)</td>
<td>Cocaine</td>
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</tr>
<tr>
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<td>Not Applicable</td>
</tr>
<tr>
<td>13</td>
<td>Male</td>
<td>26</td>
<td>Bipolar Disorder</td>
<td>Not Applicable</td>
<td>Not Applicable</td>
</tr>
</tbody>
</table>
3.2 Definition of Stigma

Because I was interested in participants’ experiences of being stigmatized, I wanted to know how they defined stigma. During the interview, I asked questions such as ‘do you know what stigma means?’, ‘how do you understand stigma?’, or ‘what does stigma mean to you?’ (Appendix E). Participants replied differently to this question: some participants seemed to see only the discrimination aspect of stigma. For instance, participant 1 said “when they treat you or talk to you or behave around you in a way that’s different than they would [treat] a normal every day person”. Similarly, participants 7 and 12 voiced that stigma happens when people do not understand a subject such as mental health and addiction thus judge and treat someone differently because this person “stands out from the norm”. Another participant simply stated “stigma, that’s being labelled” (participant 10), while for participant 11, stigma was “a type of a prejudice, type of grouping people into one category based on their life experience.”

Stigma was not an easy concept to be defined by the participants. In fact, four participants (#4, 5, 6, and 13) out of the thirteen answered “I don’t know” when I asked about the meaning of stigma. In those cases I tried to explain stigma in simple words: ‘it can be similar to discrimination, if you feel like people are treating you differently or a negative vibe you get from people because you’re different from them or if they call you names’. Either way, when I asked general questions such as ‘did you ever have any experiences at dental clinics that you did not like?’ Participants seemed to have had stigmatizing experiences even though they did not refer to such experiences as “stigma”.
3.3 Labelling

Being labelled was a large part of feeling stigmatized. Participants reported that their struggle with addiction and/or mental illness had caused them to “stand out from the norm”, and be recognized as “different”. Participants were given labels such as “alcoholic”, “addict”, “pot/crack head”, “junkie”, “loser” and “crazy”. Majority of them thought these labels were common in “slang language” that is spoken on the street or in jail but—at least based on their personal experiences—were seldom used by health professionals. However, through our conversations it became clear that even though participants had not experienced directly being labelled by health providers, they did believe that health providers including dentists labelled them “in their head”, or “in their own time”. It seems that health professionals were only different from the general population because they did not verbalize the labels and speak them “in the patient’s face” or “to the patient”. For instance, participant 5 mentioned that “[dentists don’t say it but] behind closed doors, in their head they’re thinking [about it]”. Participants felt the same way towards other health professionals as well: “I’ve had thoughts that my psychiatrists have labelled me in their own time.” (Participant 5)

It was also pointed out that health professionals used negative labels to refer to patients with addiction and/or mental illness when they were talking amongst themselves. In fact, as an example participant 10 talked about how from behind the bed curtains he could hear nurses at the Emergency Room referring to him as “junkie”.

Participants believed they had lost their identity as individuals to their labels. For example, when I asked participant 2 what being labelled meant to her, she answered “[It’s like] you’re not yourself anymore, you’re schizophrenic.” Another participant also
talked about how the labels did not allow for existence of an identity outside her struggle with substance use:

“People do not see me as a person anymore; instead they just see what they have imagined of a junkie...they only see the one dimension of junkie standing in front of them and nothing further.” (Participant 8)

In addition, participants testified about the prolonged persistence of their labels. Negative labels remain even for those who have recovered from substance use. For example, participant 2 stated:

“If you’re in AA (Alcoholic Anonymous) for 23 years, you still see an alcoholic… Like you never stop seeing the alcoholic.”

Having medical records related to substance use and/or mental illness seemed to trigger and practically serve as negative labels. Participants talked about how their experiences with health professionals were adversely affected once they learned about their status. For example, participant 8 had encountered this situation when she informed her dentist about her long list of medications.

“When I told my dentist what medications [I take for my mental disorders], [she seemed to think] I was just like some loser that couldn’t handle life.”

Similarly, another participant explained:

“I went to [an] emergency room in Victoria one time and the lady came back after checking my record and barely talking to me; she said ‘well there is nothing we can do, we can’t help you here’ and she didn’t even get to talk to me; she was going by my records.”
This quotation also illustrates ‘Discrimination’ which I discuss later on. It must be mentioned that participants whose symptoms of addiction or mental illness were not obvious did not report feeling labelled. For instance, one participant said she was not labelled often because: “Maybe I carry myself well enough not to look like a Baltic lady”. Participant 9 who had never perceived labelling from her dentists, explained:

“[Dentists did not know about my conditions because] I didn’t have any kind of schizophrenic [symptoms] …in the [dental] office I tried to be as normal as possible.”

All those who did not have overt symptoms also did not report their status to their care providers. Furthermore, one view towards labels that was different from the rest of participants’ came from participant 11 who explained labelling as categorizing people “based on their life experiences”. She used the expression “correct labelling” in her answer to my question of whether or not she had ever felt labelled by health care professionals:

“With my experiences in health care I don’t generally feel that I’ve been labelled. If I’m in a psychiatric unit, obviously I have a prerequisite…I’m labelled because I need psychiatric help so I’m a psychiatric patient so I’m labelled a psychiatric patient. If I’m a recovering addict, I’m labelled as a recovering addict because I am a recovering addict. I don’t feel I’ve ever been labelled incorrectly.”

Overall, participants recognized that they were labelled negatively by dental professionals. In the following section, I discuss how labelling becomes the basis for
stereotyping and sets into action negative images about individuals with substance use and mental health problems.

3.4 Stereotyping

Participants expressed a concern that due to having challenges with substance use and mental illness, they are often stereotyped. The majority of participants’ experiences signified one or more stereotypes that health professionals including dentists held against them. These stereotypes were being blameworthy/at fault, inferior/unworthy, unable/unwilling to change, untrustworthy, and dangerous/aggressive.

Some participants pointed out that dentists blamed them for their oral status: “They think that I wrecked my teeth and I shouldn’t have done that.” (Participant 5) Even though most participants took some level of responsibility for becoming an addict and the damage substance use had done to their health, such criticisms from dental professionals were perceived as being “misunderstood” and “not cared for” by them. In particular, participants thought it was unfair to be blamed for their lack of education and knowledge. Some talked about how they were never taught proper dental hygiene or that substances they used could deteriorate their oral health. For example, one participant was upset about the condition of his mouth and the fact that crystal meth had caused it:

“I’d never been told about these dissolvent inside drugs, how they make your teeth wear out, get cavity, root exposure, and gum disease.”

(Participant 5)

Participant 6 who confessed to brushing his teeth about of 50 times during his 20 years of addiction, explained:
“Nobody ever showed me [how to brush]. My childhood dentist showed me like that (showed a side-to-side motion with his fingers), I just brush like that. Still I don’t brush properly.”

Participants also believed that nearly all members of the society, including health providers, considered them inferior and unworthy. For example, participant 10 explained this stereotype and its relation to labelling:

“They label somebody an addict and by labelling them that makes them worthless, a burden to society.”

That participant also had several unpleasant experiences with health providers who had this stereotype: “They look down on you, talk down to you…don’t treat you [like] human.” Another participant talked about a dentist with this stereotype:

“I think that he did his job and everything but I think that he thinks less highly of me… I just know that he doesn’t think I was like a normal working, outstanding person.” (Participant 2)

Moreover, there also existed a stereotype of substance users as unable and unwilling to change. This stereotype seemed to be exclusively related to substance dependence and did not apply to mental health issues. Although it was not mentioned directly in relation to dentists, such a stereotype emerged when participants talked about their interactions with other health professionals. For example, participant 1 said:

“He [the doctor] told me ‘so you’re an alcoholic’, I said ‘yes’ and [then doctor said] ‘well, your liver’s not doing too good; If you continue you’re gonna die and I’m a pretty firm believer in that once an
alcoholic always an alcoholic. The chances of you ever getting sober is
generally pretty low and I don’t believe it can be done’.”

Many participants talked about how health professionals including dentists seemed
to think that not only were they unable to change but also unwilling to improve their
lives. Participants felt that they were viewed as having chosen to become an addict, and
this was especially frustrating for participants who described their addiction as a way of
dealing with emotional pain. For instance, participant 8 said:

“There is such a big misconception that people who use drugs, it’s a
choice and they just wanna have a fun ride. They [dentists] should
know [that] people who use are more sensitive than other people and
have been hurt immensely and eh they don’t know any other way of
covering that pain than to use drugs and until they get those tools and
work through their pain they can’t get off the drugs but to work
through that pain its excruciatingly painful and so of course it triggers
you to use more drugs.”

Another stereotype which all health professionals including dentists seemed to
endorse was untrustworthiness. This stereotype was especially demonstrated in
withholding pain medications from patients who had history of substance dependence.
Participants had many experiences regarding not being trusted with medications. For
example, participant 3 said:

“At the hospital when they found out I was a drug addict they wouldn’t
give me Percocet anymore and I was in pain. It didn’t make sense.”
Participant 11 pointed out a similar experience with her dentist who had assumed an ulterior motive in her request of pain relief: “I had issues with pain and I think he [dentist] assumed I was seeking drugs.” Yet, it must be noted that even amongst participants who were upset and angry for not receiving prescriptions, there were cases of abusing the prescribed medications. For instance, participant 8 said:

“I did have one episode that my [dentist] gave me Ativan because I was really nervous about getting this tooth worked on cause it hurt soo bad. I was supposed to take only one but I took one and didn’t feel anything so I took another and I ended up taking the entire bottle that she gave me.”

Lastly, many participants recognized that others stereotyped them as dangerous and aggressive:

“It’s like putting a group of people under the same subject, like all people who have mental issues are aggressive.” (Participant 12)

I asked this participant how he thought others felt about him, to which he replied “they are careful, they are scared... probably afraid of the craziness...the swing moods or something.” While this stereotype was mainly mentioned regarding the general public, participant 3 felt her current dentist appeared agitated when treating her. She said that “Sometimes he’s [the dentist] afraid of me, he shakes, he’s nervous.”

Many participants asserted that people who stigmatize them do so because they do not understand addiction and mental illness properly. They agreed that stigma especially at the level of stereotyping is consequent to lack of knowledge of the stigmatizers. For example, one participant explained:
“Before I got into the heavy drug use that I got into I myself didn’t realize why that gentleman would be on the street begging for money to go get high. [Now I understand] he’s not begging for money to get high, he’s begging for money so he doesn’t get dope sick that day so I just have more of an awareness. Stereotyping is bound to happen wherever you go because just the lack of information, lack of education on the other person’s part and they’re not necessarily at fault because of that, it’s just what they know.” (Participant 11)

Another participant pointed out the social aspect of substance use and mental health which are often overlooked:

“They don’t quite understand that maybe we grew up in a dysfunctional home or why can’t we communicate ... and why we turn to drugs.”

(Participant 7)

Participants clearly thought that ignorance about issues that typically surround addiction and mental illness were the source of the stigma they were experiencing. Interestingly, one participant explained that “older” health professionals were more likely than younger ones to stigmatize them. She said:

“The older doctors or dentists, you know the old fashion ones... might be a little bit sceptical... the older ones are kind of scary.” (Participant 9)

3.5 Social Exclusion or Separation

A feeling of separation from others and being socially isolated was brought up by the majority of participants. For instance participant 6 said:
“People who were not on drugs did not wanna hang out with me... after my nervous breakdown I didn’t have any friends really.”

The majority of the participants mentioned that even close family members did not want to be associated with them anymore. One participant said:

“All my family and my friends started separating from me [when they realized I’m using drugs]... they kinda turned their back.” (Participant 5)

Feelings of being avoided and excluded were not limited to interactions with family, friends and community but were also experienced in health care centers. Many dentists seemed to want to avoid or minimize social interactions with patients who had addiction and mental illness. This desire for social distance was manifested in various actions. Some dentists rejected patients once they were informed or guessed the patients’ substance use and mental health status while some others appeared to minimize their interactions with them by shortening the length of the appointment. For instance, participants acknowledged that some dentists performed the procedure too quickly, did not wait long enough for anaesthetics to become effective, were impatient when explaining oral hygiene, and did not answer their questions. Participant 4 mentioned about a former dentist of his:

“He was just in it for the money... He’s just the type that just wants you in and out so he can have another patient... he just wanted to, you know, take as many people as possible.”
Interestingly, one participant who earlier in the interview had talked about his dentist “doing a fast job” explained that he actually wished that appointments were shorter.

“Before [I came to rehab] I [had] a lot of negative thinking, a lot of worry, like I wanna get out, I wanted them to do it fast. Now I don’t think that way.” (Participant 6)

The theme of social exclusion also emerged when participants talked about their experiences with the receptionists:

“[Receptionists at one dental clinic] just sat over there and went about their thing. [They] don’t engage with you or anything. I know they’re busy and they have their job but you could just feel it.” (Participant 2)

Another participant also mentioned how she was neglected by the receptionist at a dental office:

“She [the receptionist] was saying hi to everybody and when I said hi she didn’t say hi back and she went to the back room on the phone. It was like she got uncomfortable when she saw me... she was offering people tea but didn’t offer me any.” (Participant 8)

Furthermore, some participants explained feelings of social avoidance as mutual. Namely, not only they were avoided by others because they had addiction and/or mental illness but also there was a tendency for self-isolation:

“When I was using I did feel isolated because I didn’t really wanna socialize with anybody because I felt embarrassed and didn’t want anyone else to know so I isolated myself practically.” (Participant 9)
3.6 Discrimination

Participants talked about a great variety of other discriminatory behaviours in the form of rejection, negligence, negative attitude, substandard care and manipulation. Many of participants’ experiences involved being rejected by health professionals. Participant 2, for example, explained being rejected by an Emergency Room nurse while another participant who expressed feeling “hurt” had a similar experience with her family physician of many years:

“When I told him [the family doctor] I’m coming here to rehab, his face turned different and ... he told me he didn’t want me to be his client...

He won’t be my doctor because I did use.” (Participant 7)

This participant then continued by saying that she was “scared” because when she finishes rehab she would not have a doctor. The direct and extreme type of rejection exemplified in the quotes above was not seen in dental settings. Instead, dentists seemed to make excuses to indirectly reject patients whom they were reluctant to see. The reasons participants were given for being refused were related to their disability insurance. For instance, participant 3 said once she wasn’t covered under her mother’s insurance anymore, she had to find another dentist who would take her insurance.

“He [the family dentist] didn’t know how to access the disability insurance or the welfare insurance so he stopped seeing me after that.”

In fact, several participants said that some dentists had directly told them that the government would not pay them the amount that they usually charge. Participant 6 explained:

\[IV \text{ 1000 per 2 years, according to the Ministry of Social Development and Social Innovation} \]
“She did some work…and she said I have more work to do [but] she told me to go to [another clinic].”

When I asked this participant whether he was given a reason for being sent to another clinic, he told me that the dentist had said it was cheaper there and one would get more out of their money. While he described the situation in an indifferent manner, not all participants who had this kind of experience took it so well. Some participants were upset for being shuffled between dentists due to their type of insurance. In addition to financial problems, some also mentioned other issues such as their unpunctuality and having communicable diseases (e.g., Hepatitis C) as possible reasons some dentists refuse to see them:

“Also they know I have Hep C and a lot of people are paranoid, I don’t know how easy it’s transmitted through oral but I had a perfectly healthy son” (Participant 10)

Another very common complaint from participants was health professionals’ inattentiveness and negligence towards them. The essence of this negligence can be captured by a short quote from participant 5 about his mental health team: “They’re always ignoring me when I have a need.”

In dental settings, participants felt neglected mostly when they sensed a lack of proper communication or when they thought the dentist was not trying to relieve their pain. Participants pointed out many experiences with dentists which lacked effective communication. In general, these experiences were essentially characterized by the dentist not speaking to them. More specifically, participants talked about dental appointments during which the dentist did not answer their questions, describe the
procedure or explain the treatment options. For example, participant 8 was very irritated about a dentist who had not explained that her tooth could be saved:

“Why didn’t she offer me the option?! [she could] say it’s gonna cost you this much to have it pulled out, this much to have it salvaged; are you sure you don’t wanna go this way cause it’s not like absolutely unsalvageable. That I wish she did, but she did not.”

Besides lack of communication, another set of experiences involving negligence was related to dental professionals’ ineffective management of pain, regarding both post-operative pain medication and local anesthesia. For instance, many participants said they were ignored by their dentist when they indicated pain during a procedure:

“I said it really really hurts but he [the dentist] wouldn’t give me any more freezing and I was in so much pain and I wanted to die!”

(Participant 3)

Nevertheless, what made these experiences even harder for the participants was not receiving any acknowledgment or comfort from the dentist when they expressed discomfort. Participant 5 said:

“My last dentist, I guess he never put enough freezing in it. It wasn’t comfortable. It felt like he wasn’t even making sure I was ok!”

The general inattentiveness that many participants described was closely related to the negative attitude of dentists when interacting with them. Negative attitude was one of the broadest themes that emerged from the interviews. It was an aspect of interaction with health professionals that participants could not exactly describe but they referred to it as a
vibe or feeling that they had noticed. For instance, when I asked participant 11 if she remembered having any negative interaction with health professional, she answered:

“I don’t know that there is anything that would be a bad experience just per se, just maybe getting a vibe from them that they’re aware of my history and maybe treating me not as couth.”

Similarly, this vibe or feeling was reported with respect to dental professionals too. One participant said: “It was different... but I don’t know, it’s just a feeling I got off of them.” (Participant 1)

Some of the terms that participants used in an attempt to explain the negative attitudes of dental professionals were: “unfriendly, cold, irritable, rude, disrespectful, judgmental, uncaring, abrupt, gruff, and harsh”. An aspect of health professionals’ negative attitude which participants identified easily was the tone of voice or the language in which they were spoken to. Participant 9 explained how she was frequently insulted and yelled at by her mental health team. Many other participants also pointed out that some health providers talked to them in a “hostile, vicious, ironic or condescending” language. For example one participant said:

“I told him [doctor] I was feeling really good before my nervous breakdown and he said ‘well show me the cars and houses if you were doing so well’.” (Participant 6)

Experiences with dental professionals did not indicate the level of hostility that participants mentioned regarding hospital staff, doctors, or mental health teams but some participants did perceive a “disrespectful” or “judgmental” tone of voice from their
dentist. Moreover, a quote that is worth mentioning came from participant 1. He recalled visiting one clinic where all the dentists spoke in an authoritarian manner:

“I think they were authoritative, they just [said] you gotta start doing this!..., it felt more like ‘this is what you gotta do, do it!’” (He imitated a commanding voice when quoting the dentists)

Furthermore, under the domain of discrimination, there was also a theme of ‘substandard treatments’. Many participants felt that the quality of care that they were provided was poor. For example, one participant talked about her experience at a psychiatric ward: “I can’t immediately come off of Benzo(diazepines) but one of them [nurses] tried to do it.” (Participant 11)

With regard to dental professionals, ‘substandard treatments’ was brought up by participants mainly when they described the dentist’s decision to extract teeth that could potentially be saved. For instance, participant 3 who at the age of 28 only had ten teeth left in her mouth stated that “[the dentist] said he will just pull the teeth now. He won’t bother having them fixed....” Another participant who was concerned about losing all his teeth also explained:

“I have more teeth than most addicts but I’m losing them now. I don’t have that many! I don’t wanna be like my dad, he didn’t have any and he wasn’t even an addict...A lot of times they [dentists] would just pull the tooth rather than work on it, rather than do what they have to do to save it... I’ve had 2 teeth ripped out like that. They could be saved to work but they figured it was easier just to pull it.” (Participant 10)
Participants also commented on aspects of professional ethics related to the provision of unnecessary procedures. For instance participant 1 explained:

“I had unlimited dental from my work so sometimes I think he took advantage of me. He fixed things that didn’t really need fixing... he was replacing fillings to the newest and best stuff.”

Similarly, another participant said:

“I think they took advantage of the fact that I’m on the 1000\(^\text{v}\), lots of x-rays! Probably unnecessary x-rays...I think that’s just cash grab.”

While participants felt “taken advantage of”, they said they “did not care” since they did not have to pay anything.

3.7 Power

Being labelled, stereotyped and discriminated against by health professionals lead to feelings of powerless and not having control over situations. When I asked participants to describe feeling powerless in health care settings, the responses were very similar. For instance, participant 5 used the negative experiences which he had with the Emergency Room staff to explain this feeling:

“When I can’t do anything about it, I can’t do anything about what they’re saying to me. I don’t have control over what they’re gonna do to me.”

Participant 10 called abuse of power “bullying” and like the quote above, he explained it as a situation created by health professionals about which “there is nothing you can do”.

\(^{\text{v}}\) He was referring to 1000$ per 2 years as in the disability insurance.
With regard to experiences in dental settings, it seemed that receiving dental treatments and even merely sitting in the dental chair was disempowering to some participants. For example, participant 8 said:

“It made me feel very vulnerable and uncomfortable because I’m stuck there [on the dental chair] with this thing [rubber dam] in my mouth; I cannot get up and leave. He can say anything or do anything he wants to me.”

Similarly, when I asked participant 3 if she ever felt powerless in dental clinics she answered: “When I’m getting my teeth pulled.” Moreover, lack of proper communication-discussed under Discrimination seemed to add to this feeling of not having power and control, and in particular for patients who had dental anxiety, this caused extreme stress. Participant 7 who described one of her dental appointments as the “weirdest and hardest experience” she had ever had, said:

“He doesn’t always explain everything, I felt ‘what are they doing? What are they putting in my mouth? What’s going on?’ It freaked me out!”

Misuse of power by health professionals was frequently brought up when participants talked about their experiences of interacting with health professionals. Most of what was discussed under the domain of “Discrimination” exemplifies the unethical exercise of power. This misuse of power by health providers in turn disempowered participants. As an example, many participants expressed feeling powerless and helpless when dentists (mis)used their power to withhold pain medications (i.e., discrimination). Participants’ solution to avoiding disempowerment was to cover up their conditions as
much as possible. Indeed, many participants talked about past experiences of being discriminated against subsequent to revealing their addiction and mental illness. One participant explained:

“I disclose too much information sometimes and when I say that, the conversation would turn or stop or something like that or turn an uncomfortable feeling like there is something wrong with me.”

(Participant 2)

Another participant talked about her previous experience with a nurse who, in her opinion, had misused her position of authority:

“I’m just assuming I’m answering the questions that I think she’s [nurse] required to ask. Then I realize she’s just making apparent small talk to judge me…she digs to get personal information out of me because I’m in a position where I would be more open to her because she is in a position of authority and so I spill all the stuff and then I realized [that] I didn’t have to. She was just a complete bitch to me after.” (Participant 8)

With health providers, while none of the participants had any problem reporting their mental health diagnosis, they all wished to keep the information regarding their substance use private. Participants mentioned that they could not lie to the physicians who could find out about their condition through test results or medical records but dentists were likely to not be informed. Participant 9 explained:
“Well they [doctors] would know more by checking around doing blood test, or urine test so I would have to tell them the truth but [the] dentist, he’s not gonna check in to those kind of things so I don’t say anything.”

When I asked participants about their reasoning for hiding their substance use from dental professionals, their answers varied. Some mentioned feeling embarrassed and not wanting to be judged or discriminated against (e.g., get less pain medications) while others even questioned the necessity of informing the dentists. For instance, some participants said “it is none of their business” or “it’s my private life”.

One participant in particular strongly believed that dentists do not need to know about her substance use and talked extensively about this topic. She had a reasonable justification for her belief:

“I do believe that if it were needed to know for safety reasons of any kind, given the prevalence of drug addiction and not just regular drug but prescription drugs and everything, I would assume that there would be a question that they ask me and then I would tell them. Given the fact that they don’t have that question on the form, I feel pretty confident that they don’t need that information.” (Participant 8)

Even though participants said they would not voluntarily share their substance use problems with any dentist, all except for one thought they would provide the information if they were specifically asked. For instance, participant 7 said:

“They all ask if I’m smoking but they never asked about the extra stuff... if he asked I would’ve said it but if not then I wouldn’t. I wouldn’t volunteer that information unless it was suggested.”
Participant 9 was the only one who said she would still not tell her dentist. Her quote below shows the level of danger and hardship she and many in her condition would undergo in order to keep their status private:

“I'm embarrassed to say such things. You know it just seems like taboo, you shouldn’t be doing, using substances and you know it’s a hidden thing... I still wouldn’t really (tell)... I know the consequences but I doubt that I [would] still say anything and [will] just face the consequences.”

3.8 Non-Stigmatizing Experiences

Even though I focused on participants’ experiences of being stigmatized in dental settings, it is important to note that not all experiences mentioned during the interviews were stigmatizing. Participants pointed out experiences with at least one dentist which lacked stigma, and were characterized by care and understanding. When talking about the qualities of these dental professionals, participants used numerous terms including but not limited to “caring, nice, patient, courteous, gentle, kind, helpful, and fair”. Moreover, receptionists of these dentists were mentioned by some participants and were described as “welcoming, friendly and accommodating (about scheduling appointments)”. Moreover, receptionists of these dentists were mentioned by some participants and were described as “welcoming, friendly and accommodating (about scheduling appointments)”.

The positive regard which participants talked about was translated through effective interpersonal skills of the dental professionals. Participants seemed to be very conscious of the dentist’s actions and emotional responsiveness. They noticed when the dentist made eye contact, spoke in a pleasant voice, took the time to explain the procedure(s) step by step, tried to calm them down about the pain and perhaps most importantly, did
not look/talk down to them. For example, Participant 2 explained her interaction with a dentist she had seen only a few days before our interview:

“I thought he [dentist] was very awesome and gentle and caring. He asked lots of questions and, not lots of questions but like ‘are you doing ok?’ and stopped and everything. I liked that. That was so cool. He made it comfortable, like if I closed my eyes, or I squinted my eyes he would say ‘are you ok?’ or ‘is everything alright?’ or like when I was in the chair making sure that I was comfortable in the chair.”

Since it was rare for participants to have experiences at dental settings that did not include stigmatization, many participants who had found a dentist they had a cohesive relationship with, said they would stay with that dentist despite other inconveniences:

“I’m going to be moving onto a transitional housing which is gonna be a good Sky Train ride away, you know about 45 minute travel time and I plan on travelling back to see Dr. ----, he’s excellent!” (Participant 11)

It is important to point out that a difference existed between participants who had only mental illness and those with co-occurring mental illness and addiction. As seen in Table 1, and also discussed under Sampling, two of the participants (12 and 13) had mental illness, but no history of addiction that was shared with me. These participants’ experiences of being stigmatized were not as strong as those who also suffered from substance dependence. Especially the topic of stigma in dental settings did not seem to be relevant to either participant 12 or 13. Participant 12 talked extensively about stigma at his workplace, and generally explained how he believed the public viewed him and others with mental illness negatively. Participant 13 however did not share many stigma-related
experiences during the interview. He only very briefly mentioned the negative attitude he had perceived from some of the nurses at a mental health facility several years ago. Overall, both participants 12 and 13 firmly said they had not been stigmatized by dental professionals nor had any negative experiences in dental settings.

As mentioned at the beginning of the Results, all four domains (i.e., Labelling, Stereotyping, Discrimination and Power), and most of the themes that were discussed are linked to each other. Below, I use a quote from one of the participants to explain this interaction.

“I feel powerless when I go to hospitals. Because in the computer [they have that] I’m a user, right? so it’s like ‘what do you want? we’re not gonna give you those pills’ (yelling); ‘I’m sick can I see a mental worker?’ ‘No you can’t!’”

In this example, the nurse labelled participant “user” after seeing her medical records on the computer. She then associated negative stereotypes to the “user”; considered her as lesser and assumed she was seeking drugs (stereotype of unable to change, untrustworthy). The nurse (mis)used her power to discriminate against the patient by talking in a hostile language (negative attitude) and refusing to help (rejection). The entire experience disempowered this participant who could not control the nurse’s thoughts and actions towards her. Figure 4 illustrates the interaction of the domains and themes as presented in the example above.
There seemed to be a sequential order to the occurrence of domains during an experience that can overall be called stigmatizing. The type of stereotype and the resultant discrimination could vary from person to person or in different settings. The essential part however remained that the person with a stigmatizing condition had to be recognized as different or abnormal in a socially unacceptable manner. In the example above, if the nurse did not access to the patient’s records and could not guess the patient’s status (e.g., from her appearance or symptoms) then the rest of that interaction may have been different. Similarly, a lack of awareness about the stigmatizing condition is required for this sequence to happen. If the nurse was better educated about addiction and mental illness and understood the psychosocial issues attached to it, she would not promptly see the patient’s request for help as a “pill shopping” case. The figure below shows an
exhaustive summary of all my findings, including all the themes and subthemes and their relationship with each other. The dashed circles indicate the subthemes that could be related to Social Exclusion but I categorized under Discrimination.
Figure 5. Exhaustive map of domains and emerged themes and subthemes

**Labelling**
- In their head/in their own time
  - Standing out from the norm
  - Different
  - Abnormal
- Lack of knowledge about mental illness/addiction

**Stereotyping**

**Discrimination**
- Insufficient time for effective anaesthesia
- Not explain the options/procedure/cost/billing
- Not greet (dental team)
- Not answer questions
- Misuse of power (i.e. cause patients feel powerless)

**Power**
- Disempower (i.e. cause patients feel powerless)
- Judgemental
- Authoritative
- Tone of voice/language
- Refusing welfare insurance
- Send to another clinic
- Judgment
- Unfriendly
- Negative attitude
- Avoiding interaction
- Unworthy/inferior
- Untrustworthy
- Unable/unwilling to change
- Unconscious
- In their head/in their own time
- Alcoholic
- Drug addict
- Junkie
- Pot head
- Crack head
- Crazy
- Mentally challenged

**Labelling**

**Stereotyping**

**Discrimination**

**Power**

**Labelling**

**Stereotyping**

**Discrimination**

**Power**

**Labelling**

**Stereotyping**

**Discrimination**

**Power**
CHAPTER 4: DISCUSSION

This study sought to explore the experiences of individuals with addiction and mental illness in dental settings. The objectives were to explain what they understood from the concept of “stigma”, and how they might have experienced it in dental settings. There were several commonalities in participants’ responses in terms of self-perception of stigma, and it seemed that stigmatization from dental professionals was characterized by being labelled, stereotyped and discriminated against which left patients feeling powerless.

In terms of defining stigma, it was not particularly surprising to me that many participants struggled with verbalizing this complex concept or that some did not know what it meant at all since it remains a relatively vague construct even for social scientists. For me it was only after completing an extensive literature review that I felt I had some understanding of stigma and its related processes. Nonetheless, even those participants who were not able to define stigma per se, did bring up elements that reflected stigmatization. Components of stigma were present in their description of “experiences they did not like”, although they did not use the term “stigma”. Among those who did give me a definition of stigma, their responses did include one or more components that Link and Phelan had proposed including labelling, stereotyping and discrimination from high powers. The emerged themes also resonated with the visual model that I had designed based on how I understood stigma. (Figure 2)

Participants’ experiences of being labelled made them feel they had lost their identity and were not viewed as who they actually are, as also seen in other stigmatized groups such as overweight and HIV positive individuals. Regarding persistence of labels as discussed by participants, reports have shown that ex-alcoholics who have
successfully recovered from alcohol abuse are still viewed as “alcoholic” and are not completely accepted in environments where their history of alcoholism is known.\textsuperscript{63} Similarly, patients who receive Methadone Maintenance Therapy (MMT) are labelled and viewed negatively by society and even health care workers.\textsuperscript{64} In many cases, recovering substance users might even alter their behaviour (i.e., relapse) in such a way that it would match the negative labels which society has given them.\textsuperscript{65}

Contrary to people with stigmatizing conditions such as physical disability and facial deformity that are recognized immediately,\textsuperscript{4} an individual with addiction and/or mental illness is not always visibly different thus it may take much longer to be labelled. This is referred to as the “visibility” factor which can potentially moderate the labels and the consequent stigma that is directed towards individuals with stigmatizing attributes.\textsuperscript{61} Not only addiction and mental illness are often not readily apparent to others, but also they tend to be kept as a secret by people who suffer from them in order to prevent the labels and the stigmatized identity that such labels imply. I will present the topic of secrecy amongst stigmatized later in the discussion. When the patient was not identified as “different”, the other components of stigma did not occur either; confirming that a lack of normalcy is an essential element in the notion of labelling and stigma.\textsuperscript{4} Link and Phelan’s conceptualization had also suggested that the first step for public’s stigmatizing reactions towards a person is to identify that person as deviant from the norm of the society.\textsuperscript{6}

For one participant in particular perception of labels was in contrary to other interviews as she did not seem to see anything wrong with being labelled “psychiatric patient” or “recovering addict”. However, these labels she referred to as “correct” were different from slang terms such as junkie or crack head that most other people seemed to
dislike since they could be utilized respectfully to describe the patient’s condition as opposed to insult them. In fact, studies have suggested that different labels that seemingly carry the same meaning trigger and correspond to different levels of stigma: Cunningham et al. (1993) examining this idea showed that the same person was rated differently when his description that was provided to others included the label “drunk” instead of “alcoholic”.

In agreement with Link and Phelan’s conceptualization, my interviews revealed that labels become the basis for stereotypes as they set into action negative images about individuals with substance use and mental health problems. Participants’ experiences reflected many misconceptions and stereotypes that society and health providers in particular held against them. In fact, a study that looked at patients’ characteristics that are often stigmatized in health care showed that both addiction and mental disorders rank in the top ten most negatively stereotyped conditions. While one participant thought the “older” health providers endorsed stronger stereotypes against patients who are involved in substance use, a study which compared physicians of various age groups did not show any difference of that regard. This study however did not explore these health care workers’ education on psychosocial topics of addiction and mental health which could be more relevant, as I will discuss under implications of this thesis.

A strong stereotype against individuals with substance use and mental illness was them being blameworthy. Like my participants’ experiences in health care settings, other patients who have these conditions have also reported often being blamed for their health problems. While it is common for dental professionals to criticize their patients for their poor oral hygiene and consequent dental diseases, many patients perceived such
criticisms as a lack of empathy and understanding. From a public health perspective, blaming individuals for not having a healthy lifestyle is more problematic than beneficial, as seen amongst many smoker and obese patients. Rather, it is suggested that health professionals must take into account patient’s life situation and environmental factors such as low level of knowledge or inability to access adequate resources.

Participants also expressed that many health providers think that people who use substances and have mental disorders are inferior and unworthy. While this could be expected from the general population who may not understand these health conditions, almost all participants had perceived such stereotypes when interacting with doctors, nurses, mental health team and dentists. Other researchers too have found that even personnel of mental hospitals believe their patients are lower than normal people and some even go to the extent to say they are no longer human.

Most participants felt health providers blamed them and saw them as unworthy because of the misconception that they have chosen the lifestyle as an addict. This exposed another stereotype against the addict population: that they are unable or unwilling to change. I found this assumption to be closely related to persistence of labels which I discussed before. Namely, labels tend to remain because there is a strong stereotype that people who have history of substance dependence lack willpower and are incapable of ever becoming abstained.

Beliefs about patients choosing to live as an addict cause health providers to lose empathy for such patients.

Negative stereotypes that health professionals held against patients with substance use and mental illness e.g., considering these individuals unworthy, at fault and unwilling to change were actualized in their negative attitude and the low quality of services they
provided for these patients. Other studies that have looked at the relationship of health care providers with injecting drug users (IDUs) have shown similar findings: Physicians and nurses tend to judge IDUs and display little concern, sympathy and helping behaviours towards them. Moreh, this has been reported by other stigmatized groups of patients. For instance, a qualitative study found that hospital nurses provide less than routine care for those who they consider unworthy- e.g., a drunk person being delivered from a bar fight. Stereotyping patients and taking into account their non-medical characteristics when choosing a treatment is observed in many health professionals. Eijkman et al. (2011) found that giving doctors a vignette about the patient’s personality and appearance which are supposedly irrelevant to treatment actually altered the recommended treatment.

Health providers who stereotype patients with substance dependence as unable or unwilling to change tend to also be concerned about these patients manipulating them to obtain drugs, hence the stereotype of untrustworthiness. My interviews also showcased many instances where participants felt neglected and discriminated against due to ineffective pain management by their providers. Most participants felt they had to convince dentists that their pain was “real” to receive anaesthetics during procedures or pain medications for afterwards. As explained before, most dentists judged them as untrustworthy and completely ignored their indication of pain.

While being withheld medications was the most frequently mentioned complaint during the course of my interviews, when discussing health professionals’ mistrust towards current or ex-substance users, it is important to keep in mind the global prescription drug crisis. Canada in particular has climbed from sixth to second largest prescription-opioid
consumer in the world over the last decade. In 2013, Canadian Centre on Substance Abuse (2013) reported that prescribed pain killers are the most dangerous drugs after tobacco and alcohol, and that national actions must be taken to address this health concern. Dentists play a prominent role in preventing such abuse by their patients, and by themselves. Although several quotes from my participants seemed to confirm dentists’ hesitation about prescribing pain and anxiety relieving medications, this should not be in the price of making patients suffer. Dentists, along with other health providers, are responsible for the difficult job of creating a balance between effective pain management and the abuse of pain medications.

Regarding anaesthesia, it must be mentioned that patients with long history of substance use tend to have lowered responsiveness to local anaesthetics. Therefore, in many cases despite dentist’s use of large doses of anesthetics to achieve regional analgesia, patients may still experience pain. Again, it seemed that dentists had not communicated that with patients, and participants found them inhumane and expressed much frustration when telling me about those situations.

Despite much research showing widespread beliefs about the dangerousness of individuals with addiction and mental illness, my participants did not have too many experiences regarding this stereotype. This could be because while such beliefs are held by the majority of the population, as confirmed by some of my participants, they tend to be less endorsed by those with higher levels of education. However, one participant did mention her dentist “shaking” and being nervous around her, which brought her to tears during the interview and I decided not to probe further as she was extremely upset about it. Although being a single case during my interviews, this patient’s perception illustrated that
dental professionals should be more aware of their body language and the potential message they might be sending to the patient. The importance of nonverbal communication in dentist-patient interactions has been confirmed by many researchers.\(^8\) It must also be emphasized that the stereotype of dangerousness in most cases would directly lead to social avoidance.\(^4\) Therefore, it is likely that dental professionals who foresaw potential danger or aggression from patients with addiction and mental illness refused to see them altogether. I will discuss the topic of refusal of care later in the discussion.

The stereotypes I discussed above seemed to have lead health professionals to view patients who suffer from addiction and/or mental illness as generally “difficult”. There is evidence that certain characteristics of patients other than their physical symptoms and clinical conditions, for instance, their uncooperativeness, lower social class, fear of treatment, mental disability, or any other issue that interferes with the normal routine of treatment can affect health professionals’ perception of their patients.\(^6\) As I saw amongst my participants, it is not unusual for individuals with addiction and mental illness to possess these “difficult patient” characteristics which caused supposed inconvenience for the health providers. In fact, my participants also pointed out issues such as unpunctuality, communicable diseases, low tolerance of pain and financial problems that could contribute to and even affirm their “difficult” image in health care settings.

Through my interviews I clearly saw that negative labels and stereotypes lead to discrimination as Link and Phelan had stated.\(^6\) Participants generally thought they were treated differently by others due to their challenges with substance use and mental illness. It is suggested that labels and negative beliefs (i.e. stereotypes) about addiction and mental health cause a reaction from the public in the form of social separation. A study that looked
at the impulse to distance oneself from the mentally ill showed that the majority of people thought socializing with someone who has a mental disorder can influence their own mental health negatively. Findings about desire for social distance have been seen in connection with other stigmatizing conditions, including homelessness. In this case, Phelan et al. (1997) showed that people felt strongly about wanting to put a distance between themselves and a person described to them as homeless, were not willing to be friends with this person or ever have him/her around their community.

In health care settings, social avoidance is experienced by patients with stigmatizing conditions. For example, a great percentage of people living with HIV/AIDS (PLWHA) have suffered from social isolation and ostracism since the early years of the AIDS epidemic, and frequently face the problem of being refused health services. Such rejecting behaviours seemed to be the easiest way for health providers to achieve their desired social distance from stigmatized populations. Yet, I am not sure if such desire was also perceived by my participants when interacting with dentists.

In general, patients who are perceived as difficult, including those struggling with addiction and mental health, might be declined services. In fact, during my interviews, being rejected by health providers was discussed frequently with regard to various health care services. The experience of one of my participants mentioning that the dentist “did not know how to access the disability insurance” could have been an excuse to reject the patient. More often than not -irrespective of the patient’s condition- government-regulated plans are not welcomed by many dental clinics and dentists are typically reluctant to provide publicly funded care. There is a great amount of evidence regarding dental professionals’ increasing tendency to work in the private sector, given the dissatisfaction
with the government’s payment schemes.\footnote{In the UK, for example, the number of dentists who participate in NHS work has decreased over the past two decades, to an extent that patients in some areas have difficulty finding a dentist that would provide NHS care.} My interviews showed that some dentists in Canada also do not accept the Disability insurance as it requires them to follow the Ministry of Social Development and Social Innovation’s fee guide\footnote{which is considered lower compared to the standard fee guide. While theoretically some dentists may argue that they have the right to choose their patients, referral of patients is only acceptable if it is under the human rights legislation, and is in accordance with dental professionals’ Code of Ethics\footnote{meaning it is done in the patient’s best interest. For instance, if a dentist due to lack of skills or experience or knowledge feels inadequate to provide care for a patient who requires special treatments, he or she may choose not to see that patient. This however was not the case for my participants who perceived to have been unethically refused services merely because of issues related to financial compensation. In addition, it must be emphasized that even in a legitimate case of patient dismissal, the dentist is ethically responsible to make arrangements ensuring that the patient will receive appropriate care in a timely manner. Then again, based on my interviews some dentists did not guide the patients they were dismissing on where they could receive the care they needed.}}; meaning it is done in the patient’s best interest. For instance, if a dentist due to lack of skills or experience or knowledge feels inadequate to provide care for a patient who requires special treatments, he or she may choose not to see that patient. This however was not the case for my participants who perceived to have been unethically refused services merely because of issues related to financial compensation. In addition, it must be emphasized that even in a legitimate case of patient dismissal, the dentist is ethically responsible to make arrangements ensuring that the patient will receive appropriate care in a timely manner. Then again, based on my interviews some dentists did not guide the patients they were dismissing on where they could receive the care they needed.

As explained before, while rejection was dentists’ most common response to negative stereotypes they held against patients with addiction and mental health problems, my interviews found that amongst those who did not reject these patients, many seemed to have rushed through the appointment. The impact of stigmatizing conditions on the length of appointment has also been reported with regard to obese patients who, compared with
thinner patients, receive less time and less health education from health providers. It must be mentioned that while social avoidance could be only one of the motives behind rushing appointments, the work style of dentists might also be a factor contributing to the apparent rush. Some dental professionals with an entrepreneurial attitude believe that “time is money”, and might be more concerned about the financial results as opposed to the quality of services. Especially, for such dentists the fact that these patients usually pay with the Disability Insurance could have been another reason to shorten the appointment so they can see patients who would pay the regular (i.e., higher) fees. Supporting evidence from the UK shows that dentists under NHS spend less time on their patients than they would under private care.

Furthermore, impatience staying seated in the dental chair through an appointment, which a few of my participants recalled, could have in some cases added to the dentist’s fast-pace work. This however shows that many dental professionals are not prepared for managing such patients with special circumstances. Research on the topic of dental considerations for the disabled emphasizes that length of appointments must be customized to the patient’s disabilities and circumstances; meaning, a longer procedure might have to be scheduled over several shorter appointments that can be tolerated by the particular patient.

When I asked about the general perception of their dental visits, several participants remembered being socially avoided by receptionists of some dental clinics. Despite evidence proving that patients’ health care experience is not limited to just the treatment or examination by clinician, more often than not receptionists do not acknowledge themselves as part of the healing environment. Several studies have shown that patients do notice
whether the receptionists at health care centres are friendly and helpful to them or not. Therefore, it is important for dental professionals to make their entire team aware of their ability to contribute to the creation of an overall positive experience for the patients. Contrary to findings about negative reactions from other patients, none of my participants brought up any unpleasing encounters with other patients in the waiting room, even after I specifically asked them about it.

Many participants discussed perceiving a general negligence from health professionals when seeking care. A survey held at the psychiatric unit of Hong Kong University showed that 21% of patients felt neglected by their health providers. Moreover, such neglect is reported by other stigmatized groups including AIDS patients in many African countries who do not receive much attention from doctors and nurses at the hospitals.

Inattentiveness of health professionals was described by my participants mainly in terms of improper communication. As exemplified by many quotes, dentists frequently failed to communicate effectively with their patients particularly in terms of chief complaint and treatment options. This is however not limited to dental professionals as studies have shown that many cancer patients feel that they are forced by their oncologist to start a certain treatment without being told all their options. Even though health providers may believe they are choosing the best treatment for their patient, this is not how the patients perceive the situation.

Essentially, all patients, not just those who have substance dependence and mental health issues, demand and expect information when they visit a health professional. It is the patient’s right to be informed about his or her health concerns and treatment choices.
Dental professionals must keep in mind that patients with substance use and mental illness often need more clarifications and attention during their dental visits than other patients.

All participants pointed out one or more situations in which a health professional behaved negatively towards them. The impolite and offending language and tone of health professionals that my participants brought up, is commonly experienced by patients with other stigmatizing conditions like schizophrenia, HIV, and obesity. These groups of patients have all reported being insulted, disrespected and even cursed at by some of their health providers. Furthermore, the authoritarian tone of voice which one participant remembered about his previous dentist is often deliberately adopted by health providers as a professional attitude. However, unfortunately it is generally perceived as uncaring by patients; the provider is considered emotionally absent and patients feel that they are seen as a problem that must be solved as opposed to a person who has a problem.

Many participants felt the quality of health services they received was lower than what other patients were provided. As in most other discriminatory behaviours, substandard care is also documented in relation to other stigmatized populations including prisoners, prostitutes, attempted suicide patients, PLWHA and the obese. Health professionals may even make less effort to save these patients’ lives, as experienced by one of my participants who was discharged from the hospital in the midst of withdrawal period of his detoxification. Regarding dental care, as voiced by participants in my study, substandard treatment was seen in the form of extracting potentially salvageable teeth. This could perhaps, as explained before, be a dental professionals’ reaction to the stereotype that patients with substance use and mental illness are unworthy, at fault, and have chosen their lifestyle thus do not deserve the more complex and time-consuming treatment. In
addition, it has been found that dentists may refrain from preferred or necessary treatments according to a patient’s level of motivation. Especially, patients who are struggling with substance use and mental health are seen as unmotivated to improve their oral health. Nevertheless, a dentist’s decision to extract a potentially fixable tooth cannot be justified by a patient’s lack of motivation and should not be influenced by it either.

Several of my participants felt some dentists took advantage of them by providing them treatments which in their opinion were unnecessary. A significant increase in the number of dentists has made dentistry a competitive business, and over-servicing has been on a rise as way to compensate for the limited number of patients. There is even evidence that the 6-monthly dental checks that are recommended by most dentists are actually not needed. Over-servicing to some degree can be unintentional and due to old-fashioned philosophy of treatment amongst some dentists. Yet, a study that closely looked at the disparity between needs and treatments showed that unnecessary procedures were provided more frequently by fee-for-service than salaried dentists. Therefore, financial motive plays a key role in this drill, fill, bill dilemma.

Relationships of my participants with their health providers were influenced by an uneven share of power which made them feel powerless. Power has deep roots in provider-patient relationship; especially mind power and social power are prominent in health professionals’ interactions with their patients. Health professionals have the mind power because of their knowledge and skills, and they benefit from social power due to their high social status.

As illustrated in my findings, a supposedly routine procedure can be perceived as very distressful by certain patients depending on their cognitive abilities, emotional status,
previous dental experiences and the resultant dental anxiety. The stress and anxiety that my participants expressed corresponded to their feeling of not having control. In fact, much research on the relationship between sense of control and stress has shown that perceived loss of control induces stress in people. Therefore, in order to help patients, particularly the more vulnerable who are more prone to feeling powerless, cope with their decreased sense of power more emphasis must be put on communication, empathy and rapport skills.

Even when health providers communicate well, openly include their patients in decision-making and do not misuse their power, the balance of power tends to favour them. Equality of power in the provider-patient relationship is almost impossible and there always exists a potential to misuse the power. In particular, my participants seemed to feel that health providers may misuse their power and discriminate against them if they found out about their history of addiction. Therefore, not surprisingly, they were reluctant to share their substance use with health professionals.

While some researchers have suggested that keeping information from the health provider is in fact a type of misuse of power by patients, secrecy is found to be one of the coping strategies often adopted by stigmatized individuals. In other words, hiding stigmatizing conditions from health providers can be a coping mechanism by patients to avoid becoming disempowered. In fact, such secrecy can protect the self from losing social power when interacting with professionals who by default have the higher power position. This sense of secrecy has been seen amongst many women who have had abortions, as well as PLWHA and gay men. All these people, like my participants, are concerned with
confrontation or other negative reactions they may receive if they make their status public.\textsuperscript{62, 108}

Since participants said they would report their substance use disorders if explicitly asked by dentists, perhaps, a question specifically asking about substance use should be added to dental clinics’ patient registration form. Such question would clear the ambiguity for patients by indicating that the information about substance use is actually needed by the dentist. Plus, it would prevent having to ask such questions during a seemingly casual talk with the patient.

Despite the negative experiences, positive relationships with the dentists were filled with respect and empathy. Such positive regard in the form of acceptance and affirmation is pleasing to all patients,\textsuperscript{109} especially to those with addiction and mental illness since they are used to encountering much stigmatization from health providers.\textsuperscript{21, 23}

All facets of non-stigmatizing interactions which participants described were parallel to findings of Loignon et al. (2010) who showed that dentists’ positive approach to providing care for underprivileged patients involved being non-judgmental, understanding and empathetic towards these patients as well as taking the time to engage with them in conversations. Interestingly, some of the points mentioned by those dentists, such as importance of eye contact or tone of voice, were identical to what my participants had identified in their dentists.\textsuperscript{94} Based on my interviews, the core of participants’ positive experiences seemed to be a dentist’s ability to show compassion through effective communication. While communication facilitated a positive dentist-patient relationship by balancing the power between the two sides, patients felt satisfied and empowered.\textsuperscript{69}

Unfortunately, the pressure of clinical dentistry often causes dentists to underestimate the
significance of communication and empathy. Dental professionals’ non-stigmatizing actions and attitudes like those mentioned by my participants are partially, if not entirely, due to their education and social awareness about addiction and mental illness.

4.1 Revised Visual Model

Overall, even though participants did not always use the terms that Link and Phelan had suggested, their descriptions of stigma in essence were similar to the conceptualization of stigma which I discussed in the introduction of this thesis. While Link and Phelan’s conceptualization of stigma and the visual model I designed based on my understanding of it (Figure 2) considered social exclusion as one of the 5 components of stigma, based on my interviews I realized that -at least in dental settings- social exclusion, although an aspect of stigma, was in fact part of being treated differently and should be categorized under discrimination and not separately. Namely, social exclusion was existent but hidden within themes such as rejection, rushing of appointments, and being uncommunicative. Therefore, the graphic presentation of stigma (Figure 2) which I had designed previous to collecting data was modified in order to reflect the specific context of dental settings. (Figure 6)
4.2 Conclusion

I can conclude from the findings of this study that:

- My participants and perhaps most other individuals with substance dependence and mental health issues perceive stigma from some dental professionals.

- Many experiences of stigmatization in dental settings were similar to those in other health care centres.

- Link and Phelan’s conceptualization of stigma could be used to understand the nature of stigma the participants described.

- Stigma in dental settings was a combination of being labelled, stereotyped, and discriminated against by dentists who were misusing their position of power.
- Poor or lack of knowledge about addiction and mental illness was suggested as the core origin of stigma directed towards individuals with these conditions.

- Dental professional’s effective communication with patients can improve the provider-patient relationship, and lessen the stigma perceived by those patients who have problems related to addiction and mental illness.

4.3 Implications

I believe that overall my research is a step towards the betterment of dental services for people who struggle with substance use and/or mental disorders, as well as those with prior history of these stigmatizing conditions. Findings of this study would allow dental professionals understand these patients’ low self-esteem which might make them over-interpret situations. In particular, my research reinforced the importance of communication, taking the time to listen to the patients and being mindful to body language and non-verbal cues when interacting with such patients. Dental educators (for both undergraduate and graduate levels) would also benefit from this research as the data gathered directly from those with addiction and mental illness can provide them information on what needs to be integrated into the current educational programs about these vulnerable and high-needs populations.

In recent years, medical and dental education curricula in North America have placed more emphasis on the importance of social awareness for students.110 Presenting facts through lectures or simply telling students to stop having presumptions about certain populations has not always been beneficial, and sometimes have even led to contradictory results.111 Nevertheless, the influence of education on changing stereotypes of mental health and addiction should not be underestimated as many researchers who have
examined different intervention methods in minimizing stigma have highlighted the significance of education as an effective tool.\textsuperscript{112} Especially, education through a focus on humanity is found to change people’s beliefs and attitudes towards stigmatizing conditions. Some of the most successful interventions include: presenting positive stories about individuals with such conditions; directly exposing health-disciplines students to stigmatized groups of patients; as well as incorporating self-reflection techniques in training future health professionals.\textsuperscript{10,113}

As a matter of fact, UBC Faculty of Dentistry has a three-hour session on the topic of “Addiction in Dentistry” which follows similar interventions. This session is part of the Professionalism and Community Service (PACS) module for first year DMD student, and its details have been discussed previously by Brondani and Pattanaporn (2013). It starts with a guest lecture followed by several speeches by individuals who themselves struggle with substance use, and concludes with a question and answer period between students and speakers. Subsequent to the session, students are encouraged to write reflectively - maximum 500 words- about their own emotional and intellectual response to the session. Reflections typically include -but are not limited to- feelings, thoughts and change of beliefs that the session had induced in students.\textsuperscript{114}

I had access to a set of 20 anonymous reflection assignments from academic years 2008-09, 2009-10, and 2010-11. These reflective data were primarily used for a separate study\textsuperscript{114} but the already obtained ethics approval from BREB had permitted the future use of the data beyond the conclusions of that first research project. It must be noted that it was not in the scope of this thesis to thematically analyze the students’ reflections as I solely
used them to illustrate and emphasize the difference that educational interventions can make in students’ perspective towards patients with stigmatizing conditions.

Many of my participants testified that dentists (and dental students) should listen to individuals who had undergone substance dependence in order to view this condition differently. In fact, the speeches given by community members with a history of addiction during this PACS session shed light to the same issue. For instance, one student wrote:

“‘I felt that this session really made me think about addiction as I never thought before. Normally, when I think about addiction, I immediately think of the negative aspects like drug and alcohol abuse. People usually see 'drug addicts’ differently or treat them differently. After today's session, I feel that I view addiction slightly differently. Some people do not choose to take drugs or choose to live a life as an addict; some of them just took a wrong turn and went downhill from there.’” (Student from Year 2008-2009)

These reflections were powerful because they were in agreement with what my participants had expressed through the interviews: that addiction was not a choice but rather triggered by their life circumstances. In other words, the session had shown the inaccuracy of the stereotype that substance users are at fault for their situation. Also because the speakers had successfully overcome their addiction, the stereotype of inability to change, which based on my interviews many health professionals had, was challenged.

Some of the students also pointed out that they had learned the importance of being understanding and responsive when providing care for patients who suffer from substance dependence. Through this session, students had become aware of the shame and
embarrassment that many of stigmatized individuals feel when they seek dental care. The general impact of the session was especially seen in the following quote:

“I thought it was very interesting when he said how ashamed he was when he went to these visits and how much it meant to him to be treated like any other human being. I will definitely remember this when I'm treating patients in the future and will always try my best to treat everyone equally and with respect because every single patient, no matter where they come from or what issues they may be dealing with, has a right to this.” (Student from Year 2009-2010)

Even though this session did not address mental illness and its common co-morbidity with substance use, students’ reflections revealed that they had become familiar with several subjects that were brought up by my participants during the interviews. Indeed, a more comprehensive and effective educational model on mental health is the Community Service Learning (CSL) offered by the Dental Hygiene Program at UBC. Through this CSL course, in addition to attending didactic sessions on mental illness and substance use, students provide hygiene services to patients who have mental health issues, and critically reflect on their experiences in the community by journal writing and having group discussions with other students. The combination of lectures and exposure to these patients through rotations can lead to a high degree of social awareness in the students. However, it must be noted that whether or not the impact of such educational curricula remains upon graduation, when these students are ready to serve their communities, is unknown.²³¹¹⁰,¹¹⁵ Perhaps, continued education courses could be of value to further sensitize dental professionals towards the issues of addiction and mental health and the provision of care
that is humanistic and de-stigmatized. In fact, I have conducted a brief pilot study in which I employed a vignette (Appendix F) built from my participants’ interviews.

This preliminary study consisted of a discussion with a group of dentists whom I conveniently recruited from the UBC Dentistry Graduate Programs through email invitations. The discussion was held with five participants from a variety of programs (Endodontics (1), Prosthodontics (2), and Master of Science (2)) in a private room of UBC Dentistry’s Graduate Commons Room. Discussion lasted for approximately 45 minutes and food was served prior to it. Participants gave written consent (Appendix G) to being audio-recorded.

The situational vignette I developed focused on some of the most frequently mentioned issues of all the 13 interviews I had conducted. A paper copy of the vignette was given to each participating dentist so they could read it in their own pace and write down their ideas if they wished. It must be noted that I did not transcribe or analyze the recordings. I do however use some of the quotes from the discussion to emphasize certain points. I asked participants to comment upon this real scenario, discuss their thoughts about the two dentists mentioned in the vignette, and talk about how they personally would treat Mary (the vignette character) or any patient in a similar situation. I found that dentists in my group discussion easily expressed their ideas and felt comfortable commenting on each other’s opinions. Many issues such as treatment options, costs of dental care, pain management and abuse of prescribed medications were mentioned.

The participating dentists felt they did not have sufficient medical history and clinical information about the patient to suggest treatment plans. Nonetheless, one of them did comment on the treatment decision of the dentist:
“If the patient doesn’t have a lot of motivation or she is still using substances and her oral hygiene is very poor then it could be justified to remove all teeth.”

Regarding patient’s oral hygiene, another participant also agreed with the statement above that it would be hard to change behaviours. He raised the issue of listening to the patient to understand the psychosocial problems that have led to her poor oral status. On the other hand, some participants who were more focused on finding a clinical solution believed “they have to address the chief concern”.

The potential danger of patient abusing pain medications was brought up as they most thought that “the patient had one goal... just wanted the pain medications to be prescribed”. All participating dentists also commented on the ineffectiveness of anaesthetics for patients with substance abuse, and thought the dentist might have reached the maximum permitted amount, and they contemplated that perhaps the dentist “didn’t do anything wrong.” They, however, seemed to agree that dentists must communicate better with their patients and should explain “why certain treatments can or cannot be done, what the limitations and regulations are”.

Issues related to the affordability of dental services and how dentists do not have much control over it were also brought up. One participant suggested that the dentist in the vignette should have handled the situation differently.

“Our role as dentists is to provide options for the patients, there are ones that you can afford, ones that you can’t afford. If she doesn’t have the money, sometimes there are resources like free clinics that we can reach to see if they can help her. The responsibility of the dentist is to make sure
when she walks out of his door she knows where to go; you at least have to direct her to resources to get her pain sorted out.”

Finally, participants commented on the dentist claiming not to know how to access the welfare insurance by saying that “the amount is lower and [some dentists] don’t deal with insurance; it just makes their office work easier.”

Overall, the vignette seemed to have facilitated the initiation of the discussion and allowed participants to think about different dimensions of treating a patient with substance abuse and mental illness, while providing the patient’s perspective about receiving dental care. However, further studies are needed to not only fully test and evaluate the use of such vignette, but also to involve other groups of practicing dentists and dental hygienists.

4.4 Limitations

While qualitative research is the most appropriate method for detailed exploration of a sensitive issue like the stigma attached to addiction and mental illness, there are some potential limitations to this type of research.

First, my study included a relatively small number of interviewee participants who may not be typical of the population with addiction and mental illness in Canada or elsewhere. In particular, all participants had sought professional help and were under treatment at the time of the interview. Therefore, generalizability of the findings is limited and must be done with caution.

Second, the interview situation may have been intimidating to some of the participants and despite my efforts they may have been embarrassed to share their stories. It is possible that certain experiences or feelings were not mentioned in order to avoid judgment from a non-user.
Third, another drawback of my study was that in addition to substance use and mental illness, almost all participants had other stigmatizing characteristics such as being poor, on social assistance/welfare insurance or having Hepatitis C. In other words, the stigmatization from dental professionals might have not been exclusively due to addiction and mental illness but rather a response to a combination of all these stigmatizing conditions.

Moreover, I acknowledge that since I did not observe any of the participants’ experiences at dental settings, the reported stigma might have actually been a misinterpretation of the situation.

Finally, my research did not address self-stigma that individuals suffering from substance dependence and mental health might have against themselves. Self-stigma could have influenced participants to over-interpret the otherwise non-stigmatizing interactions with dental professionals. Nevertheless, this work was the first qualitative study to interview patients with substance use and mental illness to understand their perception of being stigmatized by dental professionals. Future studies can perhaps attempt to test the model of “Stigma of mental health and addiction in dental settings” which I developed based on my findings.

4.5 Final Comments

I believe my research question was an indirect reflection of several aspects of my life: my undergraduate studies, my mother’s career, and the career I want to pursue. A few years ago, my mother, who worked as a family doctor for years, started working as a physician and counsellor at a harm reduction clinic. The clinic is part of a project designed by the World Health Organization (WHO) and is indirectly regulated by it. The goal of
harm reduction clinics is to minimize the damaging consequences of risky and illegal behaviours (e.g., drug abuse), and my mother found it very rewarding to be involved in the project. At the time my mother made this job transition, I was in my second year of Bachelor of Science in Biopsychology. As part of one of my courses I was learning about the biological mechanism of addiction as well as the behavioural manifestation of this condition. Therefore, I understood the difficulties of working with the addiction population, and recognized the challenging work my mother had chosen. I began to become curious about my mother’s experiences, and my curiosity led me to have long conversations with her about her and her co-workers’ interactions with drug users. As a result, in the course of the past few years, I gained an appreciation for the key role that compassionate health providers play in the lives of drug users.

As an aspiring dentist, it had become important to me to identify the role of a dentist with regard to this group of patients who are among the most vulnerable to be affected by the “inverse care law”, i.e., high needs but low availability of oral health services. Hence, when I started my Master’s of Craniofacial Science, I decided to focus my thesis on dental public health, particularly on the subject of substance users’ experiences with dental professionals in order to reach a better understanding of the substance user-dentist relationship.

Prior to any attempts for data collection, I volunteered at the Burnaby Centre for Mental Health and Addiction, a site that was recommended by a committee member for recruitment. There, I learned the nuances of forming relationship with those struggling with addiction and mental health. I spent time with them at the center’s Recreation Room, where we played ping pong, and watched television. Even though at first I was hesitant of
how to make connections with the clients, I initiated small talk with them as an ice-breaker and gradually made them feel at ease with me so we could establish communication. After only few visits to the center, I could feel that I was building a bond with some of the clients and they would greet me when I arrived. Some engaged in long conversations with me and seemed to trust me as they shared with me their life stories without fear of being judged. At this point, interviewing became less awkward for participants as most people who wanted to participate had seen me around the centre and knew who I was. I especially sensed that our interactions, including the interview, were very meaningful to them because of my genuine respect and empathy for them, feelings that they do not perceive often from many others.

I need to add that my biggest concern in doing this research was that even though I believed I did not hold stigma against those with substance use disorders, the stigmatizing thoughts which I was exposed to through school and media, may have affected me without me being aware of them. However, I anticipated that, even if I did have stigmatizing beliefs, my study would help me grasp a more in-depth perspective on the issues that substance users struggle with, and thus reduce the possible stigmas. And now that I have completed my research I can say that in fact I felt comfortable spending time with them and did not find myself judging them. Instead, I found my experience of interviewing with those suffering from substance dependence and mental illness very rewarding. It gives me a sense of pride to know that I was able to make these individuals feel accepted and understood. Most importantly, the main takeaway for me as an aspiring dentist is to transfer the skills and the responsiveness which I learnt from these experiences to my future practice and caring for this and other underprivileged and vulnerable patient
populations. I am also hopeful that during my upcoming DMD study period I will utilize my research findings by collaborating with my instructors to better educate other DMD students, our future dental providers, about serving patients with addiction and mental health issues.
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APPENDIX A: RESULTS OF NARRATIVE SEARCH

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46. Stigma: Notes on the management of spoiled identity. Goffman E.
47. Conceptualizing stigma. Link, BG, Phelan, JC.
49. Stigma: Ignorance, prejudice or discrimination? Thornicroft G, Rose, D, Kassam, A, Sartorius N.
51. A community based programme to improve access to dental services for drug users. Charnock S, Owen S, Brookes V, Williams M.
52. Understanding the impact of stigma on people with mental illness. Corrigan PW, Watson AC.
53. Quality of life and self-stigma in individuals with schizophrenia. Tang I-C, Wu, H-C.
54. Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia. Feyissa GT, Abebe L, Girma E., Woldie M.
55. Labelling mental illness: The effects of received services and perceived stigma on life satisfaction. Rosenfield S.
57. Social psychology of stigma. Major B, O’Brien, LT.
58. Stigma and its public health implications. Link, BG, Phelan JC.
59. The pain persists: How social exclusion affects individuals with schizophrenia. Perry Y1, Henry JD, Sethi N, Grisham JR.
62. The Relationship between Drug User Stigma and Depression among Inner-City Drug Users in Baltimore, MD. Latkin C, Davey-Rothwell M, Yang JY, Crawford N.
Would you like to tell us about your experiences with dentists?

You are invited to participate in a research entitled, *Addiction-Related Stigma: Experiences of Drug Users with Dentists*, which will be conducted by a UBC master student.

**Are you the one?**
- ☑ Resident of Burnaby Mental Health and Addiction Centre
- ☑ Have ever been to a dental clinic
- ☑ willing to do a max 60 minute interview
- ☑ Understand and speak English

**If so, we would like to hear from you!**
You will receive a **$10 Tim Hortons Card** for participation in the study!!
Interested?! Please talk to Melissa and she'll tell you more!
Her office is downstairs in the recreation room
APPENDIX C: INTERVIEW CONSENT FORM
THE UNIVERSITY OF BRITISH COLUMBIA

Consent Form

Addiction-Related Stigma: Experiences of Drug Users with Dental Professionals

Principal Investigator: Dr. Mario Brondani, UBC, School of Dentistry

Primary Contact: Rana Alan, MSc Student, University of British Columbia

This research is being conducted as a requirement for a MSc thesis. You will be informed regarding the use of and access to the information provided. All identifying information will be removed from information collected during interviews.

Purpose
The purpose of this study is to understand stigmatizing experiences of drug users with dental professionals.

Study Procedures
You will be asked to participate in a 60 minute interview once in this facility. This interview will be audio-recorded for our records. During the interview, you will be asked to talk about your experiences of stigma in the society and particularly in dental settings. The interview will be conducted by Rana Alan. There will be an optional review of the written analysis of the interview. Including this optional review, maximum total time commitment would not exceed 3 hours.

Confidentiality
Your identity will be kept confidential. Any identifying information will be removed from interview transcripts. Audiotapes and written transcripts of the interviews will be kept in a locked filing cabinet. Any study documents stored on the computer will be file-protected. Participants will not be identified by name in any reports of the completed study.
Risks
The research study deals with a sensitive topic. While no risks are anticipated, I, Rana Alan will attempt to alleviate any potential risks to you by ensuring that you are aware of your right to stop the interview at any point if you become distressed or are unable to continue.

Remuneration/Compensation
You will receive a voucher from Burnaby Centre which you can exchange accordingly.

Contact for information about the study
For further information regarding this study, you may contact the investigators named above.

Contact for concerns about the rights of research participants
Any concerns about your rights or treatment as a participant may be directed to the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia at 604-822-8598.

Consent
Your participation in the study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without consequence to the services you receive from the Burnaby Centre, or any other institution.

My signature below indicates that I have received a copy of this consent form for your own records.

My signature indicates that you consent to participate in this study.
I agree to have my interview audio recorded.

Signature: _____________________________________________

Printed Name: __________________________________________

Date: ________________________________________________
APPENDIX D: PRE-INTERVIEW QUESTIONNAIRE

THE UNIVERSITY OF BRITISH COLUMBIA

Participant ID:

General Information:

Age_____ Gender _________

Sexual orientation_________ Ethnicity________

• What is your highest education level?
  
  Below high school _____
  
  High school diploma ____
  
  College/University degree or higher____

Medical/Insurance Information:

• Are you on any continuous medication? ________________________
  
  Yes__  No__ If yes please provide their names?____________

• What type of mental health diagnosis do you have? _________

• Do you have any medical condition or health concerns, not including mental health diagnosis? (for example, Hepatitis, HIV/AIDS, heart disease, cancer, liver/lung cirrhosis, etc)
  
  Yes__  No__ If yes, please provide their names_____________________________

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• In the past, what substance did you use the most? ____________________________

   For how long approximately? (For example, less than a year, 1 year, 2 years, etc)
   ____________________________

• Do/did you smoke any form of tobacco?
   Yes__    No__  If yes, for how long approximately? ____________________________

• Do you smoke/use marijuana?
   Yes__    No__  If yes, for how long approximately? ____________________________

• Do you have any dental insurance plan, either private or from the government (Ministry of Health – Disability, Emergency, etc)?
   Yes__    No__  I don’t know__

• In the past, how did you pay for dental work? _________________

• When was the last time you saw a dentist or dental hygienist? _________________

• What was the reason for seeing a dentist/dental hygienist? _________________

• Do you receive income assistance? ___________________________

• How would you rate your general health?
   ( ) Excellent    ( ) Very good    ( ) Good    ( ) Fair    ( ) Poor

• How would you rate the health of your mouth/teeth/dentures?
   ( ) Excellent    ( ) Very good    ( ) Good    ( ) Fair    ( ) Poor
APPENDIX E: INTERVIEW GUIDE

1. When was the last time you saw a dentist?
2. What happened during the visit?
3. How was that for you? Were you satisfied overall?
4. What does stigma mean to you?
5. Do you feel that people in your situation are stigmatized by the society? Do you yourself feel stigmatized by the society?
6. How about by health professionals? For example doctors, nurses, or pharmacists?
7. Do you feel stigmatized in a dental clinic?
8. Are your experiences in dental clinics different from experiences at other health centres (e.g., medical clinic, hospital, pharmacy)?
9. How are these experiences different?
10. How do you think dental professionals think/feel about you?
11. Why did you feel like you were being stigmatized? (For example, did you feel you were labelled? stereotyped? isolated? discriminated? powerless?)
12. Did you feel like they were treating you any differently compared to other patients? Can you give me examples of that?
13. Did you think they listened to your problems and addresses the complaints well?
14. Was it difficult for you to book an appointment with a dentist?
15. Do you think your needs with regard to dental care are met?
16. If affordability was not an issue, would you be interested in getting more dental services?
APPENDIX F: SITUATIONAL VIGNETTE

Mary is 28 years old and is currently receiving treatment for depression. She has been using crack, heroin and alcohol for 8 years. She has 10 teeth left in her mouth and says that her dentist told her *he would have to pull all her teeth now. He won’t bother having them fixed because she doesn’t have enough money*. She mentions that this dentist did not know how to access the welfare insurance, so she tried to find another dentist. Mary thinks the new dentist is nice but, according to her, he doesn’t prescribe Ativan or pain killers, and she remembers her last visit: *I said it really really hurts but he wouldn’t numb that area again and I was in so much pain and I wanted to die.*
APPENDIX G: GROUP DISCUSSION CONSENT FORM

THE UNIVERSITY OF BRITISH COLUMBIA

Consent Form

Stigma of mental health and addiction in dental settings: Experiences of patients

Principal Investigator: Dr. Mario Brondani, UBC, School of Dentistry

Primary Contact: Rana Alan, MSc Student, UBC, School of Dentistry

This research is being conducted as a requirement for a MSc thesis. You will be informed regarding the use of and access to the information provided. All identifying information will be removed from information collected during interviews.

Purpose
The purpose of this study is to understand stigmatizing experiences of substance users with dental professionals.

Study Procedures
You will be asked to participate in a 30 minute discussion. This discussion will be audio-recorded for our records. During the discussion, you will be asked to talk about a case-vignette that is presented to you. The discussion will be facilitated by Rana Alan.

Confidentiality
Your identity will be kept confidential. Any identifying information will be removed from the transcripts. Audiotapes and written transcripts of the interviews will be kept in a locked filing cabinet. Any study documents stored on the computer will be file-protected.

Contact for information about the study
For further information regarding this study, you may contact the investigators named above.

Contact for concerns about the rights of research participants
Any concerns about your rights or treatment as a participant may be directed to the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia at 604-822-8598.

Consent
Your participation in the study is entirely voluntary.

My signature indicates that I consent to participate in this study.
I agree to have my interview audio recorded.

Signature: ____________________________________________

Printed Name: ________________________________________

Date: ________________________________________________