



***Perspectives of people affected by environmental sensitivities concerning  
access to dental care, oral health, and illness***

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## **Dedication**

*I would like to dedicate my thesis to my loving husband, Faisal Mirza, for being my sunshine. Who always believed in me, supported me, and was there when I needed him. Without his love, patience, and continuous support, it would have been much harder to complete my studies.*

*To my mother, who was always present to help and support me.*

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*Only one who devotes himself to a cause with his whole strength and soul can be a true master.*

*For this reason, mastery demands all of a person*

*Albert Einstein*

## Abstract

**Introduction:** Environmental sensitivities (ES) consist of two main sub-types, electromagnetic hypersensitivities (EHS) and multiple chemical sensitivities (MCS). Approximately five percent of the Canadian population reported being affected by environmental sensitivities. Their symptoms can be numerous, notably headache, tiredness, nausea, insomnia, and distress, and touch many organs. While struggling with these symptoms, people affected strive daily to survive, limiting themselves indoors and seeking refuge from the external environment. In this particular context, we do not know how they manage their oral health and access dental care services. This information is necessary for health care providers to accommodate them and promote their oral health.

**Objective:** This study's objectives were to a) understand better how people with environmental sensitivities access dental care services; b) describe their perspective regarding their oral health; c) describe their needs regarding oral health and access to dental care.

**Methods:** We conducted a qualitative descriptive study based on semi-structured interviews with people suffering from environmental sensitivities. We recruited the participants from associations of environmentally sensitive individuals. We held the interviews over the phone, considering their health condition, which did not permit people to enter their house wearing scents. Our analytic approach followed the 6-steps method described by Braun and Clark. The research was participatory and included an advisory committee composed of three representatives of the community of people with environmental sensitivities. This committee discusses all aspects of the research, including data collection, analysis, and knowledge translation.

**Results:** The findings revealed a significant gap between the dental care system and environmentally sensitive individuals. Thus, coping with their health conditions and finding access to dental care services was a great challenge for most participants. They considered dental health very important and had to go to great lengths to consult dentists. Participants explained that it was challenging for them to access dental clinics that could fulfill their basic needs for two major

reasons: 1) dentists' lack of awareness concerning environmental sensitivities (MCS and/or EHS), and 2) the presence of fragrance, chemical products, and wireless technology in dental offices. To facilitate access, participants recommended the dental clinics be free of scent, smoke, and wireless activities, so that they could endure the clinical environment during their treatment. They also wished that the treatment modalities could be modified as per their condition, as many were sensitive to amalgam fillings, for instance.

**Conclusion:** People with environmental sensitivities struggled to access dental care services. One of the reasons is that dentists provided insufficient and inadequate quality care to them, mostly due to their lack of awareness. Most dentists indeed ignored their specific needs and failed to accommodate their requests to enhance access. Therefore, to improve their access with minimal hindrance requires a collective effort from regulatory bodies, dental professionals, and dental educators.

## Résumé

**Introduction :** Les sensibilités environnementales se composent de deux sous-types principaux : l'hypersensibilité électromagnétique et les sensibilités chimiques multiples. Environ cinq pour cent de la population canadienne a déclaré être touchée par une sensibilité environnementale. Les symptômes peuvent être nombreux et affecter de nombreux organes, incluant maux de tête, fatigue, nausée, insomnie et détresse. Tout en affrontant la maladie, ces personnes luttent quotidiennement pour leur survie, se réfugiant dans leur maison et se coupant de l'environnement extérieur. Dans ce contexte particulier, nous connaissons mal les obstacles auxquels fait face cette population pour promouvoir sa santé buccodentaire et accéder aux services de soins dentaires. Cette information est nécessaire pour que les fournisseurs de soins de santé dentaire répondent adéquatement aux besoins des personnes avec des sensibilités environnementales.

**Objectifs :** Les objectifs de cette étude étaient de mieux comprendre : a) comment les personnes ayant une sensibilité environnementale accèdent aux services de soins dentaires ; b) quelles sont leurs regards sur leur santé buccodentaire ; c) comment elles décrivent leurs besoins de santé buccodentaire et d'accès aux soins dentaires.

**Méthodes :** Nous avons entrepris une étude descriptive qualitative basée sur des entretiens semi-structurés avec des personnes souffrant de sensibilité environnementale. Nous avons recruté les participants auprès d'associations de personnes sensibles à l'environnement. Compte tenu de l'état de santé des participants, les entretiens ont été réalisés par téléphone. Les discussions ont été enregistrées puis retranscrites et analysées selon la méthode thématique en 6 étapes de Braun et Clark. L'étude était participative et comprenait un comité consultatif composé de trois représentants de la communauté des personnes ayant des sensibilités environnementales. Ce comité a abordé tous les aspects du projet de recherche, y compris la collecte et l'analyse des données et le transfert des connaissances.

Résultats : Les résultats montrent un écart important entre le système de santé buccodentaire et les personnes sensibles à l'environnement. Ainsi, la prise en charge de leur santé buccodentaire et l'accès aux services de soins dentaires constituaient de grands défis pour la plupart des participants. Ces derniers considéraient leur santé dentaire comme très importante et faisaient d'énormes efforts pour consulter le dentiste. Les participants ont souligné deux grandes barrières en termes d'accès : 1) le manque de sensibilisation des dentistes sur les sensibilités chimiques et l'hypersensibilité électromagnétique ; 2) la présence de parfums, de produits chimiques et de technologie sans fil dans les cliniques dentaires. Pour faciliter l'accès, les participants recommandent aux cliniques dentaires de devenir des environnements sans parfum ni fumée. Ils souhaitent également que les modalités de traitement puissent être modifiées selon leur état, car beaucoup sont sensibles aux matériaux dentaires comme les amalgames.

**Conclusions :** Les personnes sensibles à l'environnement semblent privées d'un accès adéquat aux services de soins dentaires, notamment parce que les dentistes méconnaissent leurs besoins et tiennent peu compte de leurs demandes d'accommodement. Par conséquent, des efforts collectifs sont nécessaires de la part des organismes de régulation professionnelle, des professionnels dentaires, et des éducateurs dentaires.

## Chapter 1: Introduction

How people react to the environment may vary from a person to another. Some individuals show an adverse reaction to peanuts, while many do not show a similar response. This type of sensitivity is usually associated with the term "allergic reaction," and generally, people are familiar with this terminology. However, multiple chemical sensitivities and electromagnetic hypersensitivities are little-known to people. In a given environment, with the presence of many environmental triggers, a certain percentage of people may react to much lower levels of chemicals and electromagnetic waves than an average person.

Environmental sensitivities is an umbrella term that covers many aspects of sensitivities with commonly overlapping conditions [1, 2]. In this study, two aspects of environmental sensitivities, namely electromagnetic hypersensitivities and multiple chemical sensitivities, are discussed. Cullen introduced the term multiple chemical sensitivities in the scientific literature in 1987 [3], whereas the term idiopathic environmental intolerance was first used for electromagnetic hypersensitivities in a workshop organized in Berlin in 1996 [3-5]. It needs to be noted that various authors have utilized different terminologies for the two subtypes of environmental sensitivities: chemical intolerance, chemical hypersensitivity, idiopathic environmental hypersensitivity, idiopathic environmental intolerance, environmental illness, medically unexplained physical symptoms (MUPS), sensitivity-related illnesses (SRI), electrical hypersensitivity and idiopathic environmental intolerance with attribution to electromagnetic field (IEI-EMF) [1, 6-12]. In this thesis, I used the most common descriptive terms: "multiple chemical sensitivities" and "electromagnetic hypersensitivities."

There is a lack of consensus to define multiple chemical sensitivities and electromagnetic hypersensitivities [13], which have been described as "the most puzzling clinical entity in the 1980s". In a survey [14] among physicians, the majority defined multiple chemical sensitivities as "a condition accompanied by a chronic history of reproducible symptoms that occur after low-level exposures to multiple chemically unrelated substances and further indicated that the condition resolves upon removal of the incitants." The symptoms are diverse and include headache, tiredness, nausea, lethargy, muscle aches, memory difficulties, and fatigue [15].

The triggering chemicals are numerous and found in household cleaning agents, pesticides, perfumes, fresh paints, newsprint, and numerous other petrochemical-based products [16].

Besides, electromagnetic hypersensitivities was defined in a 1994, WHO workshop as "an acquired disorder with multiple recurrent symptoms associated with diverse environmental factors tolerated by the majority of people and not explained by any psychiatric or psychological disorder" [5]. Electromagnetic hypersensitivities has also been defined as a condition with a "variety of physical symptoms without a clear pathological basis that is attributed by the patients to relatively low-level exposure to non-ionizing electromagnetic fields (EMF), emitted by sources such as mobile phone devices and base stations, high-voltage overhead powerlines, computer equipment, and domestic appliances" [17]. In terms of symptoms, the neurological effects are prominent with headaches, fatigue, difficulties concentrating, insomnia, and distress [18-22].

As there are controversies around the definitions, no one has really emerged yet. The main difficulties toward clinical consensus on multiple chemical sensitivities and electromagnetic hypersensitivities classification are related to various factors [13]: (i) The wide range of symptoms and signs linked to exposure of environmental triggers; (ii) the diversity among affected people, reacting based on individual sensitivity; (iii) the absence of proven pathogenic mechanisms and therefore straightforward diagnostic criteria; (iv) the wide range of probable environmental triggers; and (v) the absence of precise dose-dependent reactions.

Worldwide, environmental sensitivities is not recognized to its fullest and remains a very poorly addressed phenomenon: while physicians still debate the existence of this condition, doubt their symptoms, people suffer [10]. Furthermore, doctors lack knowledge and awareness of environmental sensitivities and often leave them unheard, neglected, and marginalized [23]. Affected people struggle to survive and are left with the urge to flee from modern society [24]. Access to health care is one of the issues they face; Gibson [9] noted that the common barrier to receiving treatment was their inability to find a health care professional who understands their condition.

This said, the literature is extremely scarce on the experience of people with environmental sensitivities related to oral health and access to dental care. We thus ignore the barriers they may face when in need of dental services and, ultimately, how they manage their oral health. This information is essential for the dental care system to accommodate this marginalized groups of people and respond to their basic needs. Therefore, our study seeks to investigate the perspectives of people concerning oral health, oral illnesses, and access to dental care services.

## **Chapter 2: Literature review**

### **2.1 Multiple chemical sensitivities**

#### **2.1.1 What is multiple chemical sensitivities?**

Multiple chemical sensitivities is a perplexing and poorly understood phenomenon that was initially identified by Rudolph in the 1940s but became progressively discussed only in the 1980s [4]. Multiple chemical sensitivities fall into the category of contested illnesses as it has yet not uniformly and officially reached a diagnostic code in the medical profession [10]. Therefore, to acknowledge multiple chemical sensitivities as a disease, a consensus was reached in 1989 by a group of physicians. It stipulated that, in order to diagnose individuals with this disease, physicians need to identify the five following criteria: (1) the symptoms are consistent with repeated exposure to the chemicals, (2) the condition is long-term (chronic), (3) a low level of exposure cause symptoms, (4) symptoms are improved when incitants are removed, and (5) symptoms are caused by multiple types of chemicals and their derivatives [25]. Ten years later, this consensus was still valid, but doctors and researchers requested to add a 6<sup>th</sup> criterion referring to the involvement of multiple organs [25-27].

Therefore, multiple chemical sensitivities is considered a complex, puzzling condition as the symptoms and the triggering chemicals might completely differ from a person to another [28]. For example, the triggering factor could be the continuous chronic exposure to a low level of a chemical substance, such as a mold in a house; it could also be a single exposure to a large number of chemicals, such as oil spillage [26]. For instance, Gibson et al. presented that 21% of their studied population in the USA exhibited symptoms of multiple chemical sensitivities due to single massive chemical exposure as a triggering factor [15]. However, the main triggering factors are common in daily life and include perfumes, diesel exhausts, molds, household cleaning products, air fresheners, new carpets, and fresh paint [9, 10, 26]. According to Randolph and Ashford et al., many people with multiple chemical sensitivities also report multiple food sensitivities, including caffeine, alcohol, and medications [4]. Table 1 describes types and examples of products that may trigger reactions in susceptible individuals and initiate multiple chemical sensitivities.

**Table 1. Types and examples of triggering agents that may cause multiple chemical sensitivities [26]**

<b>Types of causative agents</b>	<b>Examples of causative agents</b>
<b>Volatile organic compounds</b>	Formaldehyde Solvents Scents Off-gassing mixtures Petrochemicals
<b>Combustion products</b>	Tobacco smoke Vehicle exhaust Barbecue or wood smoke
<b>Microbial products</b>	Molds Bacteria Mycotoxins Mould or bacterial metabolites
<b>Pesticides</b>	Insecticides Herbicides Fungicides Algaecides
<b>Natural inhalants</b>	Pollens Animal dander
<b>Foods</b>	Allergenic proteins Preservatives Flavouring agents Individual-specific foods (e.g. pungent foods)
<b>Other factors</b>	Noise

Multiple chemical sensitivities can affect many organs related to the respiratory, neurological, dermatological, gastrointestinal, and endocrine systems, neurological symptoms being the most common [26]. Several studies also showed that the symptoms vary from person to person; they are very mild for some people but life-debilitating for others [9, 26]. The scope of symptoms, like their severity, can thus vary a lot [10]; the most common are headache and memory loss, but tiredness, nausea, lethargy, muscle aches, and depression can also occur [10, 15, 26, 29]. Since there are no conclusive diagnostic tests available for multiple chemical sensitivities, physicians mainly rely on patients' symptoms and, in particular, on four common combinations of symptoms: (1) having a

stronger sense of smell, (2) difficulty concentrating, (3) feeling dull or groggy, and (4) feeling spacey [30]. Table 2 represents the symptoms and their associated body systems.

**Table 2. Multiple chemical sensitivities and their symptoms [26, 31]**

<b>Body systems</b>	<b>Symptoms</b>
<b>Nervous system</b>	Heightened sense of smell Difficulty concentrating Difficulty remembering Apparent variability in mental processes Feeling dull or groggy Feeling "spacey" Headaches Restlessness, hyperactivity, agitation, insomnia Depression Lack of coordination or balance Anxiety Seizures Tinnitus
<b>Upper respiratory system</b>	Stuffy nose, itchy nose (the "allergic salute") Blocked ears Sinus stuffiness, pain, infections
<b>Lower respiratory system</b>	Cough Wheezing, shortness of breath, heavy chest Asthma Frequent bronchitis or pneumonia
<b>Eyes</b>	Red, watery eyes Dark circles under eyes Pain in eyes Blurred, disturbed vision
<b>Gastrointestinal system</b>	Heartburn Nausea Bloating Constipation Diarrhea Abdominal pain
<b>Endocrine system</b>	Fatigue, lethargy Blood sugar fluctuations
<b>Musculoskeletal system</b>	Joint and muscle pain in the extremities and/or back Muscle twitching or spasms

	Muscle weakness
<b>Cardiovascular system</b>	Rapid or irregular heartbeat Cold extremities High or low blood pressure
<b>Skin (dermatological system)</b>	Flushing (whole body, or isolated, such as ears, nose or cheeks) Hives Eczema Other rashes Itching
<b>Genito-urinary system</b>	Frequency and urgency to urinate Painful bladder spasms

## **2.2 Electromagnetic hypersensitivities**

### **2.2.1 What is electromagnetic hypersensitivities?**

Some people suffer from hypersensitivities that are related to electromagnetic fields, which include electric and magnetic fields. Differences in voltage create electric fields; the higher the voltage difference, the stronger the field [32]; besides, magnetic fields "are created when electric current flows: thus, the greater the current, the stronger the magnetic field" [32].

There are two sources of electromagnetic fields: natural and human-made. The natural sources are present almost everywhere in our environment and include, for instance, the electric charges built during thunderstorms. In contrast, human-generated electromagnetic fields comprise of high voltage power cables, radars, broadcasting stations, or microwave ovens [11, 33]; they also include various imaging techniques used in hospitals, such as radiographic machines (x-ray) and Magnetic Resonance Imaging (MRI) scanners [32, 34]. Besides, the rapid technological advancement of the last decades resulted in the widespread use of wireless communications [11, 33, 35]. This has increased our exposure to electromagnetic field very much [36] and raised concerns about health effects of extremely low-frequency magnetic fields (extremely low-frequency magnetic fields, > 0-300Hz) and radio-frequency radiation (radio-frequency, > 3 Mhz – 300 GHz ) [35, 37].

The symptoms of electromagnetic hypersensitivity are similar to those of multiple chemical sensitivities but also fibromyalgia, chronic fatigue syndrome, and Gulf war illness [12, 38]. In a study conducted by Schreier et al., the most common complaints of individuals suffering from electromagnetic hypersensitivities were sleep disorders and headaches, affecting respectively 43 % and 34% of the people [39].

In the past ten years, the reported number of cases of electromagnetic hypersensitivities has increased enormously, probably due to the rise of electronic devices. Due to such a drastic change, researchers in Poland conducted studies [40, 41] demonstrating that people living near mobile phone base stations experienced more adverse health effects such as headaches and impaired memory than those residing further away [42].

## **2.3 Prevalence of environmental sensitivities**

### **2.3.1 Worldwide prevalence of multiple chemical sensitivities**

In the USA, several investigations have been conducted since 1990: initial ones, based solely on anecdotal evidence, suggested that 2 to 10% of the US population were hypersensitive to chemicals; subsequent studies identified nearly 15% of young college students and 37% of the elderly population with multiple chemical sensitivities. In the following years, another research conducted by Caress and Steinemann showed a similar percentage (12.6%) of individuals affected by multiple chemical sensitivities [43]. Following that study, few others conducted in the USA between 2002 and 2006 showed a prevalence of 11 to 12%. Additional studies conducted in different states of America in the subsequent years presented slightly higher (16%) prevalence [44, 45].

Compared to North America, other parts of the world, such as Denmark, showed a higher prevalence of multiple chemical sensitivities in their general population (27%) [45]. Likewise, an adult health survey in Australia (New South Wales) revealed that 25% of respondents were sensitive to chemicals [45]. Another study conducted in Sweden and Korea demonstrated that the intolerance to odors was common, reaching a prevalence of 19% [46].

Conversely, a population-based survey in Germany identified fewer people with self-reported multiple chemical sensitivities (10% less) [47].

### **2.3.2 Worldwide prevalence of electromagnetic hypersensitivities**

Worldwide, the estimated prevalence of electromagnetic hypersensitivities depends on its definition and varies according to when and where the surveys were conducted [33, 39, 48, 49]. In terms of timing, the number of self-reported electromagnetic hypersensitivities individuals has progressively increased in the last decades, especially in European countries [11]. In Austria, Germany, Switzerland, and France, multiple studies have indicated a prevalence between 1.5% and 10% of the population. Similarly, Japan and Iran reported lower prevalence rates, between 3 and 4.6% [17, 50, 51]. Other countries found higher rates; in the Netherlands, for instance, while evaluating the relationship between health complaints and electromagnetic field exposure, researchers reported 18-37% of their population being electromagnetic hypersensitivities [52]. Similarly, in Sweden and Taiwan, 13.5% of the surveyed populations reported electromagnetic hypersensitivities [53].

### **2.3.3 Multiple chemical sensitivities and environmental hypersensitivities in Canada**

In 2005, the National Survey of Work and Health of nurses in Canada reported that 3.6% of nurses were diagnosed with multiple chemical sensitivities [31, 38, 44]. Two years later, Statistics Canada disclosed that 1.2 million people (5% of Canadian) suffered from “medically unexplained physical symptoms,” which included multiple chemical sensitivities, fibromyalgia, and chronic pain [26, 38], while statistics for electromagnetic hypersensitivities remained unknown. The situation is worsening because different chemicals and technologies are introduced regularly [6]. Due to excessive exposure to various chemicals, the number of people with multiple chemical sensitivities in Canada has increased by 34% from 2005 to 2010 [54]. The prevalence of environmental sensitivities also varies according to gender and age. In 2003, a study conducted in Canada indeed showed that it was twice as higher in women than in men [38]. Multiple chemical sensitivities was also reported as more prevalent among older adults: 6.9% in the 45-64 year-old group, compared to 1.6% in the 12-24 year-old group [29, 38, 55].

Like multiple chemical sensitivities, electromagnetic hypersensitivities remains a complex and poorly understood phenomenon subjected to controversy. Presently, due to insufficient supporting evidence between the electromagnetic hypersensitivities and exposure to electromagnetic fields, Canada has not acknowledged electromagnetic hypersensitivities as a disability. In Sweden, however, electromagnetic hypersensitivities is recognized as a disease and supported under the Sweden disability Act [56].

## **2.4 Impact of environmental sensitivities on people's life**

Multiple researches has shown that living with environmental sensitivities is difficult and that little social support and interaction with friends and family has a negative impact on people affected. The other life challenges are related to the loss of jobs, homes sometimes, and a lack of access to medical and community services [9, 10, 23, 57].

### **2.4.1 Lack of social support**

For many individuals, social and family life changes after developing environmental sensitivities because friends and family members poorly understand what living with environmental sensitivities means [58]. Yet, their support is even more crucial than before because coping on their own becomes difficult. Friends and family's disbelief about environmental sensitivities pushes affected people towards loneliness, with dire consequences such as the dissolution of marriages and break-ups [7, 29, 58]. Due to these reduced social interactions and drastic changes in their lifestyle, people with environmental sensitivities tend to develop depression [1, 59] and even suicidal thoughts. According to Gibson et al., depression is a consequence of isolation as affected people seek refuge in their homes and have reduced social interactions [8].

### **2.4.2 Employment issues**

The health condition of people with environmental sensitivities often does not allow them to continue working in an exposed environment, such as exposure to air fresheners, personal care products, and cleaning products [60]. The workplace toxicity makes them continuously ill [4]; the frequent exposure deteriorates their health condition, and thus avoiding the triggering factors is their common solution. Additionally, lack of accommodations from their employers [23] worsens their health and compels them to leave their jobs, leading to anxiety, irritability, and depression [8]. To avoid such situation, employers, for instance, should ensure indoor air quality with minimal pollutants.

### **2.4.3 Homelessness**

Gibson et al. stated that one-fifth of their studied population (93/465 persons with environmental sensitivities) in the USA was homeless at some point in their life, whereas four percent (19 persons with environmental sensitivities) were homeless during the year 2015. Homelessness occurred due to two primary reasons that we will describe in the next paragraphs: 1- financial constraints 2- unsafe living places [9].

Financial strain is often related to joblessness, as 68.8% of affected people stopped working within three years after the onset of the symptoms, according to Gibson [61]. This situation makes it difficult for them to maintain their health needs, purchase essential goods, and even keep their housing [58]. It needs to be noted that the financial needs of people with environmental sensitivities may also increase due to higher costs related to personal healthcare and safe residences [26, 54]. The safety of the living place is actually a major issue. With the need to find a secure residence, most people with environmental sensitivities have a history of numerous moves, which generate repeated expenses [58]. Researchers showed that these people struggle to have a stable life and experience dire living conditions, such as sleeping in cars, small trailers, parks, or tents [9, 58].

#### **2.4.4 Lack of medical & community Access**

Access to medical and community services is often difficult for affected people due to exposure to various chemicals and electromagnetic fields within the hospital's premises and the community area. Because of this, people avoid medical care unless in case of an emergency [10]. The same phenomenon occurs in the community environment; studies showed how people with environmental sensitivities could be "devastated" by the lack of access to public areas such as community centers, public libraries, grocery stores, public buildings, and social services [23, 61]. Access to the community is then seen by many as a luxurious life [23].

#### **2.5 Controversy about environmental sensitivities**

Controversy about environmental sensitivities exists due to a lack of scientific evidence and understanding of their pathophysiology. Until now, scientists have been unable to find supporting evidence to associate multiple chemical sensitivities related symptoms with the causative agents; partially because the knowledge of this condition is still under development [62].

Several hypotheses, however, have been formulated regarding the pathophysiology of multiple chemical sensitivities. The first suggested by Randolph was about the immunologic response; it stated that multiple chemical sensitivities would be an unrecognized form of allergy or IgE-dependent hypersensitivity [63]. To date though, no supporting evidence has been found on the role of IgE. This hypothesis has eventually been replaced by one stipulating that chemicals would impair the immune system for certain individuals [63]. However, once again, no solid data has confirmed this hypothesis. Another hypothesis later emerged suggesting that multiple chemical sensitivities could be related to a neurotoxic effect of chemicals [63]. But again, studies have shown conflicting results. Finally, it has been suggested that multiple chemical sensitivities could be linked to a predisposition responsible for altered biotransformation of environmental chemicals. But even though McKeown-Eyssen et al. observed an increased risk of multiple chemical sensitivities associated with enzymes CYP2D6 and NAT2, other researchers have not been able to identify a similar link [63].

Also, since there are no known diagnostic tests for multiple chemical sensitivities, physicians base their diagnosis on patients-reported symptoms; thus, those symptoms are often linked to psychiatric problems [26]. Additionally, many researchers try to justify their participant's medical history and state of mind based on the Bradford Hill criteria [5, 26]. Austin Bradford Hill introduced nine criteria to support the causal interference between the disease and exposure; the strength of association, consistency, specificity, temporality, biological gradient, plausibility, coherence, experiment, and analogy [64]. Considering those criteria, several researchers showed an association with psychiatric, psychosomatic, or major depressive disorders [31].

Therefore, some researchers associated multiple chemical sensitivities with a psychiatric disorder because many participants exhibited symptoms similar to psychiatric patients, such as impaired concentration, memory loss, and loss of drive and energy [31]. Similarly, few researchers consider a striking resemblance between multiple chemical sensitivities and psychosomatic disorder because of common symptoms such as palpitation, dizziness, sweating, and shortness of breath [31]. Other researchers, such as Johnson et al., concluded there was an association between multiple chemical sensitivities and severe depression and anxiety, stating that 85% and 78% of their participants met the criteria for major depressive disorder (MDD) and generalized anxiety disorder (GAD), respectively [65]. In contrast, a study demonstrates that depression is the complication of multiple chemical sensitivities (an outcome) and not a pre-existing condition; showing 37.7% developed symptoms related to depression after exhibiting multiple chemical sensitivities associated symptoms. Hence, the etiology of multiple chemical sensitivities was a physiologic and not psychologic origin [43].

Similarly, researchers lack evidence to support the association between electromagnetic fields and electromagnetic hypersensitivities related symptoms. Scientists continued conducting further studies, but their analysis did not reveal any reliable and reproducible results [66]. Like multiple chemical sensitivities, electromagnetic hypersensitivities are subjects of controversy due to lack of success in proving the association between symptoms and incitants. However, researchers are actively conducting studies to find the association between cause and effects (association between electromagnetic fields and electromagnetic hypersensitivities related symptoms). On the other

hand, other researchers suggested that electromagnetic hypersensitivities is associated with various types of psychological disorders and poor health-related quality of life [35, 53].

## **2.6 Quebec dental care system**

There are two orders of government in Canada: the federal and the provincial [67]. Health care falls under the jurisdiction of the provincial governments, and each province has an insurance plan that operates under the Canada Health Act [68]. This said, the federal government finances specific groups of people: indigenous populations, Canadian armed forces, veterans, inmates in federal prisons, and refugee claimants [68, 69].

With respect to dental care, the provincial governments play a minimal role in covering costs: 90% of the dental expenses are either covered by private insurances or out of the patients' pockets (discussed in section 2.7.1) [70]. In the province of Quebec, the only dental services universally covered by the government are related to oral surgery. The *régie de l'assurance maladie du Québec* (RAMQ) also has specific programs for children under ten and social assistance recipients, which cover basic dental treatments, while the rest of the Quebec population has to pay out of their pocket [68, 71]. Table 3 represents milestones in the development of the Quebec dental care system from 1920 to 1997.

**Table 3. Important dates in the development of the Quebec dental care system [72]**

<b>1920</b>	The Quebec government formed a dental hygiene commission
<b>1969</b>	The Régie de l'assurance maladie du Québec (RAMQ) was established
<b>1970</b>	The Quebec government invested heavily in the public dental care program
<b>1971</b>	- The children's dental care program was introduced into the health insurance act and ultimately become part of RAMQ - RAMQ insured all the children under the age of 8 years
<b>1974-1982</b>	The RAMQ steadily increased insurance coverage of children from age 8 to all the children under the age of 15 years
<b>1976</b>	The program covering people on social assistance was created by the RAMQ
<b>1979</b>	A program covering prosthetic denture for people on social assistance was introduced by the RAMQ
<b>1982</b>	- Quebec introduced the preventive Dental Services Public Program

	<ul style="list-style-type: none"> <li>- Quebec limited the eligibility criteria in the children's program; 13 to 15 year-old children were not part of the children's care program anymore</li> <li>- Preventive care for children less than 11 years was not covered anymore by the RAMQ</li> <li>- People on social assistance looking for prosthetic care had to wait six months before they could receive these dental services</li> </ul>
<b>1984</b>	Individuals on social assistance had to wait for a six-month period before they could access any dental care services (except for emergency care services)
<b>1992</b>	The children's dental program was further shrunk and the coverage of children stopped when they reached the age of 10 years (children aged 10 to 15 years were thus no longer covered).
<b>1996</b>	Social assistance recipients: <ul style="list-style-type: none"> <li>1- waiting time increased from 6 to 12 months</li> <li>2- waiting period of 24 months before periodontal services</li> <li>3- Prostheses replacement frequency increased from once every 5 years to once every 8 years</li> </ul>
<b>1997</b>	The frequency of dental examinations was further restricted in the children's care program from two to one visit per year

## **2.7 Access to care**

Access to care has always been subjected to complexity and has been defined in numerous ways [73-75]. Levesque et al., who reviewed the literature on the subject, defined access to care as "the opportunity or ease with which consumers or communities can use appropriate services in proportion to their needs" [74]. In practice, one of the most used definitions of access is provided by Penchansky [76]. According to him, access includes five dimensions linking the patient and the health care system: 1- Accessibility 2- Affordability 3- Acceptability 4- Availability, and 5- Accommodation [76].

Accessibility is the ability to access the location of health care services, which also considers the time, distance, and cost for the patient. Affordability refers to the cost of the services and the ability to pay for those services. Penchansky defines acceptability as the relationship between the clients and health care providers with respect to their attitude towards each other. Availability refers to

the "adequacy" of the number of dentists, physicians, and other health care providers; it also includes health facilities and specific programs or services. Lastly, accommodation refers to assisting and accepting patients into a health care facility. It could take several forms, such as the organization of appointments, telephone services, hours of operation, or walk-in facilities [76].

### **2.7.1 Access to dental care in Canada**

Access to care is important to maintain a healthy oral cavity and improved quality of life [77, 78]. One of the crucial facets of access to care is the cost coverage for dental expenses (affordability). Thus, there are several ways to cover dental costs in Canada; the most frequently identified routes are: (1) employment-based insurances (third-party insurance), (2) private dental insurances (self-enrollment), (3) out of pocket payments and (4) government-subsidized programs.

With regards to insurance plans (private or employment-based), Bhatti et al. [77], like many others, reported that benefits of high income and a dental insurance plan were associated with easy access to dental services [77, 79-85]. Unfortunately, the Canadian Health Measure Survey, conducted between 2007 and 2009, showed that only 62 % of Canadians benefitted from private dental insurance, whereas 6% had public coverage, and the others had no coverage. Accordingly, Quiñonez et al. found that 60% of dental care services were paid through employment-based insurance, while 35% came out of patients' pockets [86]. Data also shows social inequalities related to access to dental coverage: low income and middle-income Canadians have fewer chances of benefitting from private dental insurance than the others [86].

As we briefly mentioned before, studies have repeatedly emphasized financial barriers as a leading cause of poor access to dental care [79, 85]. Consequently, low-income earners tend to face difficulties accessing dental care services and are inclined to consult dentists in case of an emergency rather than preventively [77-79, 81, 85]. Unfortunately, those in greatest needs have the littlest access to dental care; on account of this, the underprivileged and vulnerable population tends to suffer the most [78, 82].

Another important facet of access to care is acceptability. According to Penchansky's model, in order to maintain a good dentist-patient relationship, there is a need for mutual understanding, respect, and acceptability. This is not always the case, especially with underprivileged populations, such as people with a disability or people living in poverty. Studies conducted in Quebec, for instance, showed that the relationships between dentists and welfare recipients were difficult and characterized by mutual misunderstandings and lack of trust [87-89]. Likewise, in the USA, Mofidi et al. showed that people living in poverty encountered countless negative experiences with health professionals, from searching for a health care provider and obtaining a nearby appointment to long waiting times, discourtesy, and racial discrimination [90].

With respect to availability, Penchansky defined it as the balance between available services and clients' needs, while Levesque et al. referred to the physical accessibility of the services [74, 76]. With regard to the latter definition, the geographical location of the dental clinic plays an essential role. For instance, most residents in rural areas consider the traveling distance to a dental clinic difficult [89]. Physical accessibility is also a problem for people using a wheelchair is deemed inadequate and insufficient [88].

### **2.7.2 Access to care for people with environmental sensitivities**

Gibson et al. identified two main barriers faced by people with environmental sensitivities to access medical care: their inability to find a physician who understands and accommodates their needs and the fear of being exposed to multiple chemicals and electromagnetic fields in the hospital [9]. Gibson et al. also demonstrated that several factors, namely personal and household income, level of disability, course of illness (improved vs. worsened or fluctuating course), number of years ill, and education level were correlated to people with environmental sensitivities and their unmet health care needs. These unmet needs are particularly high because this population lacks access to the medical care system [9].

Moreover, in addition to their frustration of living with unmet health care needs, people with environmental sensitivities face troublesome circumstances, where most physicians lack knowledge about their condition, appropriate diagnostic methods, and treatments [10]. According

to Gibson et al. [10], each individual with environmental sensitivities needed an average of 8.6 visits with different practitioners before finding an understanding and helpful physician. During this long pathway, people encounter physicians who do not seem to take their condition seriously enough to conduct further tests, while others are hesitant to treat them to avoid worsening their condition [91]. Due to such behavior, many people feel discouraged and avoid visiting health care facilities, while others continue facing difficulties with the hope to find an understanding physician; during this struggle, people with environmental sensitivities may even develop (chronic) untreated health conditions [10].

People with environmental sensitivities face many challenges with respect to accommodation, a fundamental right of individuals without undue hardship [92]. Due to controversy and misdiagnosis (mentioned in section 2.5), many suffer stigma and, as a result, have some of their rights related to social services, social support, and insurance benefits denied [93]. In many instances, a supporting and diagnostic letter is not always provided by their health care providers to facilitate necessary accommodations at their workplace or other places; the type of accommodation required varies based on individual needs [94]. For instance, the physician letter could help avail workplace accommodation by getting access to a more scent-free location to operate work. Given that environmental sensitivities is not an acute condition, long-term accommodation at the workplace is deemed necessary. Although in 2007, the Canadian Human Rights Commission introduced a fragrance-free policy to ease access at the workplace, so far, this policy is implemented at the federal level only; nevertheless, few hospitals, schools, and private organizations in few provinces followed their foot-steps [93, 95]. Similarly, no-smoking, pesticide-free, no idling, and least-toxic cleaning policies are slowly becoming common [26]. However, there is a large discrepancy between provinces on implementing and reinforcing those policies [26]. As a result, access to care for people with environmental sensitivities is still difficult.

With respect to the fear of being exposed, numerous chemicals and telecommunication systems in hospitals and clinics hinder people's access to health care facilities [10]. To the best of our knowledge, we found no information on access to dental care for people living with environmental sensitivities.

### **2.7.3 Summary of the literature review**

There are two types of known environmental sensitivities: multiple chemical sensitivity and electromagnetic hypersensitivities. With the increasing use of various chemicals and electronic devices, the prevalence of environmental sensitivities has increased in the past few years.

People with environmental sensitivities face many challenges in their life, including understanding their condition and making sense of their symptoms. Furthermore, their continuous struggle associated with reduced access to the external world renders their life extremely difficult. Most people face stigma and disbelief, which leads many towards isolation, loneliness, and depression.

With respect to access to medical services, people with environmental sensitivities face unsupportive health care providers who often fail to diagnose their condition and provide appropriate help. Their access to medical care facilities is further compromised due to exposure to various chemicals and electronic devices. Besides, the scientific literature is scarce on people with environmental sensitivities' access to dental services; we thus do not know how they access dental care and lack information on the challenges they may face.

### Chapter 3: Aims & conceptual framework

The study aims at understanding the perspective of environmentally sensitive individuals about their oral health and their access to dental care services. More specifically, we want to comprehend how they access dental services while facing such a challenging health condition (environmental sensitivities) and what kinds of difficulties they encounter during this process. Ultimately, our goal is to ease their access to dental services and consequently contribute to improving their oral health condition.

We used a conceptual framework derived from Levesque et al. 's model of access to care [74]. This framework guided us in several aspects of our project, in particular, the construction of the interview guide (see appendix B) and the data analysis. We mainly focused on the process part of the framework, which helped us describe the chain of events, from the participant's needs for health care to the end of the care episode and the associated health care consequences.



**Figure 1. Conceptual framework for access to health adapted from Levesque et al. [74]**

## **Chapter 4: Methodology**

### **4.1 Participatory approach**

Participatory research is defined as a "systematic inquiry, with the collaboration of those affected by the issue at hand, for purposes of education and taking action or effecting change." [96] Subsequently, this approach recognizes the importance of involving affected individuals in the research process. Following this approach, we partnered with people directly affected by environmental sensitivities, which allowed them to influence the research process and permitted us to understand their situation more accurately.

#### **4.1.1 Development and composition of the research team**

This research is lead by a research team that consists of several people:

- 1- Dr. Farah Ahmed, a master's student at McGill University Faculty of Dentistry.
- 2- Dr. Christophe Bedos, an associate professor at McGill University Faculty of Dentistry.
- 3- The representatives of three associations of people with environmental sensitivities.
  - a- Ms. Jacinthe Ouellet, representative of Fondation Air et Vie.
  - b- Ms. Rohini Peris and Mr. Michel Gaudet, representative of the Association pour la santé environnementale du Québec / Environmental Health Association of Québec.
  - c- Ms. Hélène Vadeboncoeur, representative of Rassemblement ÉlectroSensibilité Québec.

We started this project when Ms. Jacinthe Ouellet contacted Dr. Christophe Bedos and informed him about her condition and how people like herself were suffering from environmental sensitivities. She brought to his attention the difficulties individuals face to access dental care and promote their health. Dr. Bedos then informed me about this issue. Environmental sensitivities was an unfamiliar subject for me and struck my attention. The more I read about multiple chemical sensitivities and electromagnetic hypersensitivities, the more I was interested in helping Ms. Jacinthe Ouellet and other people like her. Being a former dentist, I was interested in learning more about environmental sensitivities, to know how they coped with their situation and, more specifically, how they accessed dental care and took care of their oral health. As a citizen, I was

also concerned by the challenges they seemed to face and wanted to contribute to the best of my abilities.

As an initial step of the research project, Dr. Bedos and I decided to establish an advisory committee that could help us in many aspects of the study. We discussed ways to build a robust advisory committee and whom to involve in this project. A chain reaction started when Ms. Jacinthe Ouellet recommended Dr. Bedos and me to contact Ms. Hélène Vadeboncoeur (representative of Rassemblement ÉlectroSensibilité Québec), who then recommended also to include Ms. Rohini Peris and Mr. Michel Gaudet. All accepted being part of the research team.

The newly formed team started to work in the form of an advisory committee that discussed all facets of the research, such as data collection, data analysis, and knowledge translation. I provided the advisory committee with a draft of my research protocol, and based on this document, we discussed all the major points that needed reshaping and remodeling. In particular, the team helped me polish the objectives. Subsequently, I revised the interview guide several times until all the committee members were pleased with the outcome.

Ms. Jacinthe Ouellet advised us to recruit research participants from the three associations, which cumulated approximately 2500 members. The associations collectively identified around 20-30 people showing interest in this study. Furthermore, the committee members gave me the name of potential participants belonging to their respective associations and we recruited some as we progressed with the interviews. The three associations also helped interpret some of the research findings that seemed unclear to me.

The team meetings included face to face encounters, conference calls, or a combination of these two modes. We also exchanged numerous e-mails, especially when we recruited participants and finalized the interview guide. By the end of June 2018, I started my interview process; it took almost eight months to recruit and complete the 12 interviews. During years 2019 and 2020, I took a one-year maternity leave and resumed my project in April 2020.

## **4.2 Qualitative design**

We conducted a qualitative descriptive study embedded in a participatory approach. According to Sandelowski, qualitative description entails a more "comprehensive summary of an event in the everyday terms of those events" [97]. Our research objective directed us to carry out a qualitative descriptive study because this approach allows researchers to describe events experienced by people in their sequence of occurrence. As stated by Sandelowski, "the description in qualitative descriptive studies entails the presentation of the facts of the case in everyday language." [97] This approach was thus appropriate to capture the experiences of people that were environmentally sensitive [97, 98].

## **4.3 Data collection**

Various methods exist to collect data in a qualitative study, such as observation, individual interviews, and focus groups. We decided to carry out one-on-one, open-ended, semi-structured interviews because it would give us a good insight into participants' life events [99]. Since the interviews were individual, each person had a separate session to describe their experience in-depth without being intimidated by the presence of others.

We constructed the interview guide based on Levesque et al. 's framework [74] and enriched it with parts of the McGill Illness Narrative Interview guide [100]. The advisory committee contributed tremendously to make the interview guide appropriate, simple, and easy to understand. The representative of the three organizations suggested the addition of a few pertinent questions. For instance, Ms. Ouellet recommended adding a question regarding "mobile dentistry."

To facilitate the discussions, we structured the interview into five major sections: introduction, experiences related to environmental sensitivities, experiences with dental problems, experiences related to access to dental services, and a final part that included few questions concerning participants' socio-demographic characteristics. Except in the last section, the questions were open-ended and often followed by suggestions of probing questions. During the interviews, which

I conducted, I had the liberty to ask additional questions to clarify or deepen my understanding of participants' perspectives.

As I just mentioned, the interview guide started with an introduction and a few open questions ("how are you?; "can you tell me a little bit about yourself?") designed to 'break the ice' and learn briefly about the participants. This initial section provided the participants with a buffer zone to relax a little before embarking on the main subject. The second section focused on people's health conditions concerning multiple chemical sensitivities and electromagnetic hypersensitivities. The purpose was to learn about participants' experience of environmental sensitivities and allow them to recall events related to the onset of their condition. The third section addressed their dental health and various dental care experiences during their life course (before and after environmental sensitivities). Section four was a central part of the interview guide as it addressed access to dental services; the questions were organized according to the framework of access to care that we previously mentioned. Finally, the last part was designed to wrap-up the interviews and included several socio-demographic questions. After a few initial interviews, with the guidance of the advisory committee, I slightly modified the interview guide to simplify specific questions the participants had trouble comprehending.

#### **4.3.1 Sampling & recruitment**

We adopted a criterion sampling method, defined by Patton as selecting cases that meet some predetermined criteria of importance [98]. Our main criterion was to select people who reported suffering from multiple chemical sensitivities or electromagnetic sensitivities. In addition to this, participants had to be aged 18 years or more, have visited a dental clinic in the last five years, and be able to speak English or French. The rationale behind the criteria of the dental visit in the last five years was to find people who had accessed a dental clinic and were able to describe their experiences with respect to access to care.

The recruitment process took place with the help of the team members that represented the three associations; acting as "gatekeepers," they contacted their members by sending a brief e-mail presenting the study and inviting interested people to participate. Ms. Rohini and Mr. Gaudet e-

mailed the message several times at a given interval to better reach people. Ms. Ouellet also approached the Air et Vie members by sending out e-mails and posting the message on the association's website. Interested participants then contacted their respective representatives, who, in turn, provided me with contact information.

I then contacted the potential participants by phone to give them more details on the project. I described their rights and explained that they could withdraw from the project at any time without any consequences. I continued by explaining the interview's time duration and concluded the discussion by exchanging e-mail addresses or taking note of their home address to send the consent form (if not sent already by the association) (see appendix A). Finally, I booked a meeting for a phone interview at their most convenient time. It is important to mention that the participants were reluctant to be interviewed in person to avoid unnecessary exposure to chemicals or electromagnetic waves. They argued that my visit would bring outside pollutants and scented agent into their home. We thus agreed to conduct the interviews over the phone. Also, we did not consider conducting video calls (zoom or skype) as participants were suffering from electromagnetic sensitivities and thus avoided exposure to computers.

#### **4.3.2 Interviews**

I conducted phone interviews either in English or French, according to the preference of the participants. Lasting approximately ninety minutes, they were audio-recorded and transcribed in their original language (English or French). Following the principle of saturation, we decided to stop collecting data after the 12<sup>th</sup> interview; after the ninth interview, indeed, the subsequent encounters did not bring any new information and merely repeated what we had already collected [101].

At the beginning of the interview, I confirmed their consent before proceeding with the session. I reminded the participants that they could stop me anytime if they felt unwell, and we would resume the meeting when their health permits. In the end, I thanked the participants for their time and for sharing their experiences. I also asked for their permission to contact them again in case I required

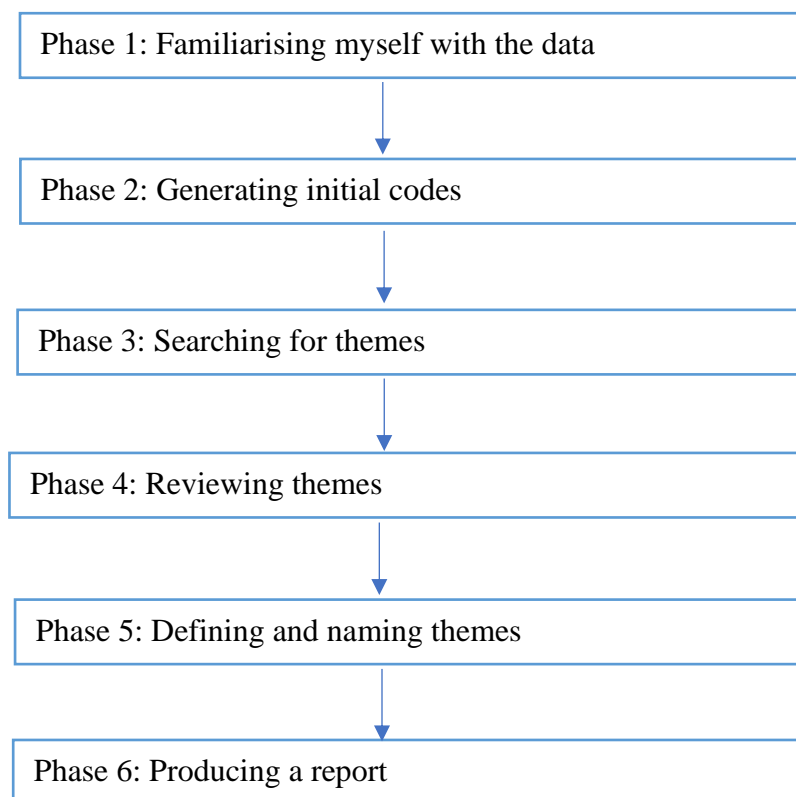
further clarification. Among all the participants, only one could not complete the interview in one session due to her health conditions; thus, we decided to schedule another meeting to complete it.

#### **4.4 Data analysis**

##### **4.4.1 Methods for analyzing data**

As previously mentioned, the interviews were audio-taped, then transcribed verbatim. I conducted a thematic analysis of the transcripts following Braun and Clark's six phases method (Figure 2) [102]. This approach focus on a realistic method that describes the "experiences, meaning, and reality of participants" [102, 103].

**Figure 2. The six phases of thematic analysis described by Braun & Clarke.**



### **Phase 1: Familiarising myself with the data**

During this phase, I familiarized myself with the data: I noted down my initial ideas during and right after the interviews; I also completed a two-page report after each interview, transcribed the data, and lastly, read and re-read the transcriptions. Subsequently, revising the data helped me familiarize myself with the content and context of the interviews. I followed Braun and Clark's recommendations and carried out active reading [102], during which I searched for patterns between participants. For instance, I asked myself questions such as: what sorts of experiences are common between participants? What kind of treatment do they prefer?

### **Phase 2: Generating initial codes**

After familiarizing myself with the data, I started generating initial codes. At first, I noted down the codes on a paper and later transferred them into a software called MAXQDA 2020 version 20.0.7. Additionally, I continued creating codes through each transcript, and as I progressed, I simultaneously modified the codes if needed. To avoid losing the meaning of the context in the transcript, I highlighted a relatively large section of the paragraph for each code. Subsequently, as I advanced, I added memos describing each code. Initially, most of the codes were data-driven, whereas, towards the end, they were mostly theory-driven [102].

### **Phase 3: Searching for themes**

In phase three, I collectively combined the codes into potential themes. Thus, I sorted the codes into similar groups, which ultimately lead to the creation of themes. During this process, I collated certain codes and classified them under sub-themes or main themes.

### **Phase 4: Reviewing themes**

During this phase, I repeatedly reviewed the themes: some made much sense, but others did not and needed to be modified or removed. At first, I started putting down the themes on paper to visualize better and categorize the ideas. Subsequently, following a method described by Miles

and Huberman, I built a matrix of my themes and sub-themes that facilitated my interpretation of the data [104]. The Figure below is an example of matrices: the columns consist of themes while the rows represent the participants (their identity was concealed by coding the participants' names with numbers). As I conducted 12 interviews, the full matrix included 12 rows. Finally, the important points were put in bullet form to summarize the situation.

**Figure 3. Sample of matrix representing interview #1**

<u>Interviews</u>	<u>How participants perceived ES</u>	<u>Discovery of their conditions</u>	<u>Challenges faced by the participants to access dental services</u>	<u>Mitigation strategies recommended by participants.</u>
1	<ul style="list-style-type: none"> <li>To have access to dental care(financially), she sold her house to get certain treatment done.<sup>1</sup></li> <li>She is coping with her life by not going out to avoid exposure. She stays inside her house for six months to recuperate from any exposure she gets.<sup>2</sup></li> <li>In the hospital, she stayed in a cold storage room instead of a normal room to avoid the symptoms (trouble breathing) due to exposure of scented room and people.<sup>3</sup></li> <li>She bargains with her neighbors and agrees into some deal to make them avoid using a scented product such as detergents at home.<sup>4</sup></li> </ul>	<ul style="list-style-type: none"> <li>She worked in real state, and she realized she could not tolerate perfume while having her clients in her car nor the building she was entering. When under the influence she couldn't function properly; lost the ability to think, cognitive impairment (realized she had MCS).<sup>5</sup></li> <li>While reading a newspaper, she read about one lady having same symptoms as her and that she tried to commit suicide and that newspaper also had details of an association that she contacted related to ES where she</li> </ul>	<ul style="list-style-type: none"> <li>For her finding, a different dental clinic was never an issue. She finally found a dentist who can fulfill most of her need and demand, and he is the only dentist she will go to for filling or other emergency treatments.<sup>8</sup></li> </ul>	<ul style="list-style-type: none"> <li>Very Important for the clinicians to be scent free for the sake of their patient health.<sup>9</sup></li> <li>Have empathy for them so they can feel comfortable.<sup>10</sup></li> <li>Mobile clinic can be a good solution for those unable to attend the clinic provided the dentist follow certain guideline to keep the patients save (awareness of their condition &amp; being scent free)<sup>11</sup> and make it affordable.</li> <li>Emphasis was on scent free environment as scent makes her sick; felt sick and had trouble breathing. The cloth washed with detergent have fragrance, perfume and the products used for skin care all affect her.<sup>12</sup></li> </ul>

<sup>1</sup> M: So, we came back to the Laurentian in Quebec my husband had a house, so we sold the house, so we had enough money to go to Mexico to try the treatment for candida, that's what it was at that point. Farah: Okay and was it successful M: it was successful enough that I could start working again yeah. Took some courses in real estate and I was able to get a job I know worked in real estate for 5 years until I crashed again so I officially stopped working in 1992. When I could no longer tolerate fire spaces, the houses I went into, the flowers they had.

<sup>2</sup> F: yah, like what are your symptoms? M: I don't go out F: Not at all?! M: I'm not, I have been near death a few times with this illness 2004 and 2005 and I had to do some underground thing to keep me alive, so I have done that for 6-month one year and 6 month next year and so that kept me alive. Now I will get (.3) now I have "woren" (I guess she mean worsen?) headache because somebody came to help me with the roof so the whole front of my head is "woren", I had pain up my spine. I know my bronchioles are inflamed and they're going to cause me a great deal of pain in very short time. I get in so much pain either it is tide and bounce, the perfume, the mothball, the cigarettes smoke, gasoline, any of the thing other people react to. So, still what I get is now I have changed, my symptoms have changed, before it would be the whole head, I couldn't concentrate and talk, I had pain to the body.

## **Phase 5: Defining and naming themes**

Naming and defining the theme was an ongoing process. Thus, I ended up with four main themes, namely how participants perceived environmental sensitivities, coping with new oral health-

related needs, challenges faced by the participants to access dental services and mitigation strategies recommended by participants.

### **Phase 6: Producing the report**

During this stage, It was essential to produce a coherent, consistent, and concise story [102]. Therefore, I reported the findings in the results section of this thesis based on the information extracted during the analytical stage. I will also produce a scientific article with the hope of publishing it in a peer-reviewed journal.

#### **4.4.2 Credibility**

Credibility is defined as the "extent to which a research account is believable and appropriate, with particular reference to the level of agreement between participants and the researcher" [105]. Lincoln and Guba suggested a series of strategies to achieve credibility in qualitative research [106].

One important strategy is to have prolonged engagement in the field by observing certain aspects such as cultural and social setting and developing a relationship with the study group. In this study, I developed partnerships with Ms. Ouellet, Ms. Peris, and Mr. Gaudet. They broadened my knowledge about environmental sensitivities and assisted in carrying out this research. With the frequent exchange of e-mails, I discussed many aspects of the research with them, including the research strategy, the development of the interview guide, the recruitment of research participants, and certain aspects of data analysis.

Another important strategy suggested by Lincoln and Guba is peer debriefing [106]. I adopted this strategy with the support of Dr. Bedos, who has expertise in public health, access to care, social justice, and poverty. After each interview, I wrote a post-interview report that I shared with him. I then debriefed with him about various aspects of the interview, including participant's experiences addressing environmental sensitivities, dental problems, and barriers faced while accessing dental care.

I also conducted triangulation procedures to enhance data interpretation [107]. I constructed a framework matrix to summarize and ease data analysis, which I then shared and discussed in depth with Dr. Bedos. Additionally, my community partners provided their perspectives on parts of the data analysis that were not clear to me, such as terms or phrases mentioned by the participants that I had difficulties interpreting. They also recommended ways to improve access to dental care.

#### **4.5 Research ethics consideration**

Dr. Bedos and I obtained the ethics approval from McGill Faculty of Medicine Institutional Review Board with the following IRB Study Number: A05-B19-18A. As I mentioned before, the participants read the consent form and signed it before the start of the interview. Since I conducted the interviews over the phone, the consent forms were either posted to the participants by Canada Post, e-mailed, or provided through the three associations. The participants returned the signed form by e-mail, Canada Post, or through their respective association. It is noteworthy that all twelve participants gave me the rights to audio-record the interviews.

I informed the participants that this project was entirely voluntary without any compensation. Additionally, I informed them about their rights, and they could withdraw from the study at any time. Furthermore, they could contact me for assistance if they had any questions or concerns about the study.

I coded the participants' names with numbers to protect their identity. The lists that match their name with the numerical codes and the interviews were password protected on my laptop and backed-up on OneDrive account. Dr. Bedos and I did not store any of the data on papers. When I submit my thesis to McGill University, I will transfer the entire data to Dr. Bedos, which he will save on the OneDrive account.

## Chapter 5: Results

In this chapter, I will first provide a brief demographic description of the participants. Then I will explain how participants discovered and coped with environmental sensitivities. After this, I will address my research objectives and describe participants' perspectives about their oral health and the ways they have managed it. I will conclude by describing the dental care pathway, the barriers, and challenges faced by the participants.

### 5.1 Description of the participants

I interviewed twelve participants, eleven women and one man, aged 40 to 83 years (Table 4). Eleven of them identified themselves as having both electromagnetic and chemical sensitivities, and one mentioned being electromagnetic hypersensitive only. As a consequence of their condition, all resided in the suburbs of Montreal. Besides, two-thirds of the participants had attended college or university, but almost all were unemployed, and only three benefited from some form of dental coverage.

**Table 4. Description of the sample**

<i>Characteristics of the participants</i>	<i>Number of participants</i>
<b>Gender</b>	
<b>Men</b>	1
<b>Women</b>	11
<b>*Age</b>	
<b>18-30</b>	0
<b>31-40</b>	0
<b>41-50</b>	1
<b>51-60</b>	4
<b>61-70</b>	5
<b>71-80</b>	1
<b>81-90</b>	0
<b>Marital Status</b>	
<b>Married</b>	5
<b>Divorced</b>	3

<b>Single</b>	4
<b>Level of Education</b>	
<b>High School</b>	3
<b>College</b>	4
<b>University</b>	5
<b>Type of ES</b>	
<b>Multiple chemical sensitivities only</b>	0
<b>Electromagnetic hypersensitivities only</b>	1
<b>Suffering from both conditions</b>	11
<b>Current Employment</b>	
<b>Yes</b>	2
<b>No</b>	10
<b>Dental Insurance</b>	
<b>Private</b>	2
<b>Public</b>	1
<b>None</b>	9

\*One participant was not comfortable mentioning their age, and thus, this characteristic was not recorded.

## **5.2 How participants perceived environmental sensitivities**

### **5.2.1 Prior to the discovery of environmental sensitivities**

Before experiencing their first symptoms related to environmental sensitivities, the participants explained they were healthy. Some had pre-existing health conditions, but they were not severe enough to affect their daily routine. Many participants were proud of their achievements in life and excelled professionally. For instance, one person mentioned that she was the first female aerospace engineer recruited by the Canadian air forces.

*Participant: I was 15 years in – air forces as an aerospace engineer. I graduated from McGill as a mechanical engineer back in 73. I was the first female to be recruited in the air forces as an aerospace engineer [...] [ Int.9]*

Another explained that traveling the world with her husband was their hobby for almost seven years. She recounted visiting several countries across the globe and working in each country before heading towards another one. One more participant explained that she had a Ph.D. degree and held professions that required traveling to Europe. The participants reported they were in good shape, outgoing, and full of life until their life changed with the onset of environmental sensitivities.

*I studied in the "Y." Then I went to Europe. I studied in France and Switzerland. Then I traveled around the world with my husband for 6 to 7 years, backpacking and working throughout the world, and I ended up in Australia. (...) after that, in -- 1976, we decided to come to Montreal because my husband is from Montreal. Then I had a daughter here [...]* [Int.4]

### **5.2.2 Discovery of environmental sensitivities**

When they experienced early symptoms, the participants had difficulty making sense of them and identifying themselves as living with multiple chemical sensitivities and/or electromagnetic hypersensitivities; labeling their condition was a long process, even a journey. With respect to multiple chemical sensitivities, the symptoms started in various ways: headache, difficulty concentrating, inability to endure fragrance, body ache, or insomnia. In the case of electromagnetic hypersensitivities, the symptoms associated with electronic devices were similar, besides earache, dizziness, and loss of equilibrium. The participants realized changes in their health and their body during various activities. In particular, visits to malls, grocery shops, and walks through aisles filled with scented products became troublesome and triggered the disturbing symptoms mentioned earlier. Exposure to perfume for more extended periods triggered headaches, dizziness, and other unpleasant feelings. People also realized that distancing themselves from that environment resulted in a speedy recovery and a stable condition, but they still wondered about the causes of their health deterioration. Being unable to correlate the symptoms with a disease was frustrating for most. Despite tests conducted at physicians' offices, they would return home undiagnosed.

Participants with electromagnetic hypersensitivities related their symptoms with electronic devices such as computers and cell phones. They acknowledged their inability to use a computer for an

extended period or surrounded by wi-fi for extended hours. They also noticed when near an electrical field, they felt electric shocks in their mouths. In the beginning, it was not clear to them why electric discharges happened near electrical fields or transmission towers, but they later linked it to the presence of amalgam fillings and metal crowns.

*Interviewer: Comment vous avez fait le lien exactement? Est-ce que vous avez lu quelque part, ou...? Comme vous avez dit que ça vous a pris 10 ans pour faire le lien entre les couronnes pis les amalgames qui faisaient les symptômes.*

*Participant: C'était quand, -- quand il y a eu des décharges électriques quand je sortais à l'extérieur parce que je ne pouvais plus sortir de chez moi, je pouvais plus faire mon épicerie, euh, je- c'était intolérable. J'avais des brûlures dans la bouche, j'avais de l'herpès sur les lèvres et dans le nez à cause de l'exposition au compteur radiofréquence à l'extérieur pis le wifi dans les magasins [...] [Int.2]*

*Participant: I hired an inspector to -- inspector I don't know I say inspector, but that's not necessarily the right term -- who looks at the levels of the electromagnetic field in the house. So that's when I became aware of that phenomenon, and I didn't know yet the term electrosensitivity applied to a person as a condition. That man discovered that I had been living in a very, very high electric field for 15 years. [...] [Int.6]*

After years of pain and suffering, some discovered the name of their condition through magazines and newspapers; others obtained information from some experts in the field of electronics or through associations assisting people suffering from environmental sensitivities, such as the Fondation Air et Vie and the Environmental Health Association of Quebec. Upon contacting those associations, the participants had a better sense of their health conditions.

*Participant: And I knew I was sick, but I didn't know what it was until I read a magazine that's called "(Notre) Maison du 21e siècle". [...] [Int.2]*

### **5.2.3 After the discovery: Coping and adapting to environmental sensitivities**

Coping with environmental sensitivities was challenging and came with a high cost: a few participants lost friends and family members, others suffered from financial constraints. The worst, according to the participants, seemed to be social isolation and a feeling of being abandoned. Participants indeed explained that friends and family were skeptical about their health conditions,

sometimes even refusing to acknowledge the existence of environmental sensitivities. Some managed to gradually convince their entourage by providing them with the scientific literature on environmental sensitivities. The latter then made changes in their lives, such as using scent-free detergents and body products, allowing the participants to stay close to them. In contrast, the participants who failed to convince their entourage had to stay away and maintain social distance, which led to the end of some friendships and family relationships.

*La famille ne voulait pas nécessairement m'accommoder. Ça dépendait des personnes. Alors plusieurs fois j'ai pas pu aller aux rencontres familiales. On se voyait 2 ou 3 fois par année, mais je ne pouvais pas y aller. Je ne pouvais pas voir mon fils, ma petite fille. Ils ne comprenaient pas [...] [Int.2]*

Besides, participants experienced a drastic change in their life due to the sudden influx of symptoms, which required extreme measures to mitigate its effects. This led them to have minimal contact with the outside world and carry out essential tasks only. It was one thing to be confined temporarily, but to lead a permanent life under such harsh confinement deteriorated their mental health and wellness. For instance, due to the severity of environmental sensitivities, a participant coped by staying indoor for six months without stepping outside of the house. The participant considered it was the only way to survive and subdue the effects of environmental sensitivities.

*Participant: I had to do some underground thing to keep me alive [not going outside], so I have done that for 6-month during one year and six months next year, and so that kept me alive. [...] [Int.1]*

Also, participants' most common struggle associated with environmental sensitivities was maintaining the balance between exposure and overexposure in the outside environment. Staying in their house and avoiding outdoor activities prevented exposure to perfume and other scented products. They also avoided pollutants, such as those present in construction zones, which triggered symptoms that, according to them, would take weeks or even months to overcome. Thus, they took preventive measures to manage their condition; they avoided purchasing scented products such as detergents, dentifrice, deodorant, and shampoo. Those with severe symptoms would take more drastic measures. For instance, some even provided their neighbors with

fragrance-free detergents to limit their exposure to scented products and thus making their neighborhood more livable.

*Participant: I am very well aware it is destroying our world, and more of us is getting sick all the time and who don't have it now -- have it, so how do I feel? Frustrated would be one thing. Um -- frustrated that I have to make a deal with my neighbors not to use Tide and Bounce because it comes to me and I buy their soap [so she buys their soap so they won't use scented soap at their house, and so eventually she won't have to smell it] so, they keep using it so I can open my window and breath. [...] [Int.1]*

Considering their high level of exposure in urban areas, most participants relocated to reside in less populated suburban areas, with a practice to go out during the least crowded hours to reduce exposure. They argued they needed a place with fewer people, fewer pollutants, and reduced electromagnetic fields. Some, for instance, mentioned the issues related to Hydro-Quebec meters. A "meter" is an apparatus or device that automatically measure the quantity of something passing through it [108]. Most buildings and apartments are now equipped with communicating meters (smart meters) that record energy hourly, report daily, and are wireless, but participants nevertheless avoided renting a place with a wireless smart meter to prevent environmental sensitivities related symptoms.

*Participant: So, I would like to live in a nicer place and away from the electromagnetic field because the higher the density, the more people there, the more number of cellphones and cellphone towers. If I move away from Wakefield, then I can get an acre of land and a house and be very far away from my neighbors. Of course, I will continue to have a non-communicating meter, but I will at least be sure to be further away from neighbors who have a communicating meter. [int.6]*

In this long process of adapting and coping with their condition, the participants explained that they self-studied and developed various measures to reduce exposure. For instance, some coped by using aluminum mosquito net-like screens around their bed with the goal of minimizing electromagnetic fields. Many wore shielding cloths, protective glasses, and carbon filter masks that, according to them, would reduce their exposure. One participant even remodeled his house by installing aluminum sheets within the walls and roof surfaces to isolate from electromagnetic

waves. It is important to mention that such changes were costly and impeded the participants' budget.

*Participant : Je me suis acheté un baldaquin du tissu là [pour mettre sur le tour de mon lit]. [...] Ce n'est pas encore idéal parce que quand je sors du lit, ben je suis dans la maison là, j'ai pas---Fait que la maison est pas assez protégée. Et puis, là dehors dans la -- je peux plus aller m'asseoir dehors, je peux plus euh prendre des marches. Ça fait longtemps je peux plus prendre des marches parce qu'il y a trop d'assouplisseur, il y a trop de gens qui font la lessive pis ça sent l'assouplisseur dans les rues. [...] [Int.11]*

*Participant : Ma maison a été adaptée pour moi.*

*Interviewer: De quelle façon?*

*Participant: Les revêtements extérieurs de la maison sont en aluminium. Donc, ça a la même apparence que comme c'est du (clabord), comme du canexel ou du TDC, mais c'est barbeaux d'aluminium à l'extérieur. La toiture c'est une toiture aluminée aussi. Elle ressemble à une toiture traditionnelle. Quand on est dans la rue on a l'impression que c'est une toiture traditionnelle, mais en réalité elle est en métal. [...] [Int.12]*

The self-studying process we mentioned let participants hypothesize that their condition resulted from prolonged exposure to hazardous substances. For instance, few participants mentioned a history of prolonged exposure to pesticides or mold and thought that environmental sensitivities developed over time. One participant explained that her continuous exposure to renovation and construction zones at her workplace, with the use of chemical substances, had progressively made her sick.

*Participant: So! Before we bought it [ house] because it was cheaper than anything else going and before we moved in! My parents-in-law filled it up with pesticides and fungicides. So, it was shortly afterward that I started reacting to just about everything. You can imagine!*

*Interviewer: So, you mean you started reacting after moving into that place.*

*Participant:: ahh! About a year later, yes! I already had a lot of pesticide poisoning in my life. Since I came from Puerto Rico where a lot of DDT [Dichlorodiphenyltrichloroethane- pesticide] was used, and they use to put in my room something called FLEET 9 [...] [Int.4]*

*A loss of voice, my throat would close because of the lung, you know! I would have a headache and confusion. I would lose my balance. All these symptoms will happen at the same time you know and conjunctivitis! Yes! I always had conjunctivitis. [...] [Int.9]*

### **5.3 Coping with new oral health-related needs**

#### **5.3.1 Perception regarding oral need**

Participants explained that once they developed environmental sensitivities, their oral needs changed drastically. They realized that their body started reacting to different dental materials that once were tolerable. For example, participants with electromagnetic hypersensitivities described their vulnerability toward amalgam fillings but also to fixed and removable metal base prostheses. They explained that wearing those dental prostheses prevented them from crossing Hydro-Quebec long transmission lines as this resulted in electric discharges within their mouth. While crossing transmission lines, the participants also experienced other symptoms: headache, dizziness, tinnitus (ringing in the ear), lethargy, or general ill-feeling. Even though they could not fully explain the cause of these electric discharges, their explanation revolved around oral galvanism, even though they did not necessarily have two different metals in their oral cavity. Dental galvanism is "the production of galvanic current in the oral cavity due to the presence of two or more dissimilar metals in dental restorations bathed in saliva, or a single metal and two electrolytes (such as saliva and pulp tissue fluid); sometimes the current may be high enough to irritate the dental pulp and cause pain" [109].

All individuals with environmental sensitivities shared the belief that amalgam fillings were harmful to health and should not be used in the oral cavity. As stated previously, participants had carried out extensive research on environmental sensitivities, whether through books, magazines, articles, or associations; all had read and learned about amalgam fillings' drawbacks. In the context of the causal relation between amalgam fillings and environmental sensitivities, participants highlighted that it was hard to undoubtedly consider amalgam fillings as a direct cause of their symptoms. They further explained that they suffered from multiple symptoms, and it was

impossible to confidently co-relate those symptoms with amalgam fillings. However, upon removal of the amalgam fillings, the participants reported making a slow but steady recovery.

*Participant: But on the way there, you go under all these big transmission lines of Hydro-Quebec, and every time I went under that, my mouth went NUTS. It just buzzes, and it hurts. It began to hurt, and I look around, and I am like O! there is an electricity line, and I had to get off the main highway, and I had to go through all the back roads trying to avoid the antenna. So, I talked to someone, and they said, "well, it is what in your MOUTH! "So, I called the dentist and said, what did you put in my mouth? And he said "amalgam," and I said, does it have mercury? and he said, "yes, with mercury." I said mercury like a thermometer!? He said, "yeah!" because they tell you when the thermometer breaks don't touch it. Why would you put it in my mouth? [...] [Int.7]*

*Participant : Elle m'a fait des tests dans la bouche avec des plombages pis elle m'a dit écoute, t'as comme un circuit électrique dans ta bouche. Tu vas enlever le plus petit, celui-là. Puis elle dit tu vas avoir presque plus rien l'électricité dans ta bouche. Alors j'ai dit ok. Je suis allée et j'ai vu un dentiste holistique à St-Jovite. Il prend toutes les précautions là. [...] [Int.10]*

Moreover, teeth extraction as a treatment strategy was not an option for most participants as they wanted to preserve and maintain their teeth. One participant, however, reported having half of her teeth (approximately 15 to 16 teeth) removed due to root infections; she explained she refused to consider endodontic treatment because she thought that it would worsen her sensitivities: "One should not keep a dead tissue within the oral cavity." The other participants were more positive about endodontic treatments, though, but their cost made it poorly accessible to them. The participants also made decisions about their metal base prosthesis based on the severity of their environmental sensitivities. In the case of severe environmental sensitivities, participants stopped wearing their metal denture base, whereas in mild cases, they used it only for eating purposes.

### **5.3.2 Oral health practice**

Maintaining oral hygiene was a challenge for the participants because of their adverse reactions to traditional toothpaste, which contained flavored ingredients, whether natural (cinnamon or mint) or artificial. The severity of the symptoms varied from person to person, allowing a few participants to use certain mildly flavored toothpaste. Another solution mentioned by severely

affected participants was to make homemade toothpaste. They explained that making toothpaste was not only cost-effective but also suitable for their health. Every participant had their way of making toothpaste based on the severity of their environmental sensitivities. For example, some used baking soda with oregano oil, while others added lemon juice as an extra ingredient; few just mixed baking soda with water. Despite their unstable financial conditions and higher price of toothpaste, many participants mentioned purchasing unflavoured and unscented toothpaste.

*Interviewer: what do you use to brush your teeth?*

*Participant: I made myself a paste with baking soda and oregano oil.*

*[...] [Int.9]*

## **5.4 Challenges faced by the participants to access dental services**

### **5.4.1 Finding a conventional or a holistic dentist**

After developing environmental sensitivities, most participants reported that they had to find another dentist as the previous one did not fulfill their requests for accommodation. Participants described two ways to find a dentist, whether conventional or holistic. Some asked their friends, family, or the associations to recommend a dentist they could trust. Consequently, they felt they did not have to inquire substantially about the clinic's safety and environment before booking an appointment. Other participants conducted an extensive search by themselves to find a dentist. This process was not an easy task, as finding a suitable dentist was dependant on several factors that we will describe in the next paragraphs: 1- the location of the dental clinic, 2- the dentist's experience with people suffering from environmental sensitivities, and 3- whether the dentist practiced the safe mercury amalgam removal technique (SMART).

The dental clinic's location was very important for the participants, who hoped to find it close to their home. This said, they avoided commercial areas because of the multiplicity of wi-fi signals. They were also concerned and afraid of being in contact with other people and crowds, which is often the case in commercial areas. These crowds, they explained, would expose them to volatile compounds such as perfume and other scented personal care products they were sensitive to.

*Participant: I went to him because his office is in the house. I have a lot of problems with a commercial building, and I figured this is going to be easier for me.*

*Interviewer: So, you did your research before going to him?!*

*Participant: I did! And I am also allergic to antibiotics, and he told me that he doesn't use antibiotics and that there are other things that they can do, and he never uses antibiotics, so I figured I am safe here, you know (laughing). He also told me that he has experience with people who have chemical sensitivities and EHS.*

*Interviewer: So you called him before going?*

*Participant: I called and then before I had the treatment, I asked to speak to him. Yeah!*

*Interviewer: Okay, and what exactly did you ask for before going to him?*

*Participant: Well, I just asked because you know I have a very high tolerance for a lot of things if I don't have to live with them, you know. So, for example, perfume or whatever.[...] [Int.5]*

Another criterion to choose dentists was their experience with people affected by environmental sensitivities; in many cases, however, participants had to lower their expectations on this aspect. According to them, there is a lack of dentists who have some experience with people affected by environmental sensitivities. Another important criterion was the dentist's ability and willingness to practice the SMART protocol, which they considered the safest procedure of amalgam fillings removal. According to them and their readings on the subject, this procedure would reduce their exposure to mercury vapors.

*Participant : Premièrement, dès que j'ai compris que j'avais ça j'ai recontacté mon dentiste que ça faisait 25 ans que j'avais. C'est lui qui m'a suggéré peut-être qu'il y avait de l'activité électrique dans ma bouche. Mais il n'était pas très ouvert. Il ne m'a pas accommodé... En tout cas. Je l'ai laissé là puis je suis passé à un autre type de dentiste. Un dentiste holistique. J'ai fait de téléphone pour m'assurer qu'il faisait le protocole de l'AIMOT. Ça c'est l'association internationale ... en tout cas c'est une association de dentiste holistique qui font un protocole sécuritaire pour le retrait des amalgames. J'en ai trouvé un, ben en fait j'en ai trouvé 3 mais il y en avait deux à Montréal pis un à Bromont. Puis je pouvais pas me permettre d'aller à Montréal, c'était trop fort en champ électromagnétique, la route. La route et l'environnement-- donc j'ai été à Bromont. [...] [Int.2]*

#### **5.4.2 Arrangement for the dental visit and transportation to the clinic**

Participants explained that their stress level was very high while preparing for the appointment because the preparation required a considerable amount of effort and arrangement before leaving

the house. They felt the need to be accompanied by their friends or family to the clinic as environmental sensitivities made their health unstable and sensitive to the external environment. As stated previously, some of the environmental sensitivities triggering factors are outdoor pollutants, scented products, and electromagnetic fields. Those incitants were encountered by the participants along the route, making them sick. For instance, one participant explained that having a friend with her in the car saved her from having an accident because she had "lost the ability to drive and had no idea what she was doing." Her friend made her stop the car and took over the driving. She realized that day the severity of her condition and has avoided driving for more than a few minutes since, always asking someone to drive her to the dentist. In brief, the participants would ask a friend or a relative to accompany them for their safety and, at times, for the safety of others.

*Participant : Ben, c'est sûr que c'est loin. J'ai eu besoin d'avoir quelqu'un avec moi pour me voyager parce que pas loin d'une heure que je vienne d'ici.*

*Interviewer : Ah c'est assez loin.*

*Participant : C'est quand même loin.*

*Interviewer : Oui, mais pis comment vous débrouillez pour vous déplacer parce que je sais c'est pas facile--*

*Participant : Euh, ben là j'ai eu l'aide de mes enfants qui ont acceptés de... J'ai même, j'ai un de mes enfants qui travaille avec mon mari pis euh y'en a un qui a pris un congé une journée pour pouvoir m'accompagner. [...] [Int.10]*

Participants' general health condition was often an issue when planning or preparing a dental visit, as the severity of their symptoms sometimes prevented them from leaving the house. For example, a participant explained being so severely affected that she became bedridden and weakened to the point that her "verbal communication converted to sign language." Even those who suffered from less severe symptoms had issues to overcome. Before leaving the house, they had to wear various protections that would minimize or delay the symptoms of multiple chemical sensitivities and electromagnetic hypersensitivities: mask or nose plugs, body shield, and in some instances, protective glasses. The participants considered the mask as a useful device to filter unwanted particles and gases. The nose plugs, they said, prevented them from smelling odors arising from perfumes and other scented personal care products. Besides, the body shield and the protective glasses represented an extra layer of protection between the participants' bodies and incitants. Participants' choices of personal protective equipment (PPE) depended on the severity of their

condition. Some only wore masks and body shields, whereas others felt they had to wear almost all the listed protective wears.

For some participants, the symptoms occurred immediately after the exposure to the outside world, whereas others exhibited delayed reactions occurring hours or days after exposure. The immediate reactions they described were various, including runny eyes, headaches, and even difficulties breathing and palpitations. The delayed reactions comprised insomnia and loss of cognitive balance.

*Participant: The problem was going to the dentist because I was reacting to everything! In February, when the damage happened, ahh by March! I had to get out of the building. I went to my doctor, and I had to stop working, and by May, in my own home, I had to throw everything out that had a fragrance. I had perfume and all the cleaning products. I could not go out without a mask. I could not go to public places. [...] [Int.8]*

Overall, the participants explained that the ride from home to the clinic was never smooth as it consisted of continuous exposure to air pollution, scented products, gasoline fumes, and many wireless devices. Fortunately, most of them managed to find a suitable dental clinic within their area, but some had to travel far to access dental care services.

#### **5.4.3 Being accommodated by the dentist**

A common practice described by the participants was to call the dental office and ask for some form of accommodation before finalizing their appointment. They usually requested early morning appointments to avoid encountering a cluster of people in the waiting room. They also asked the dental team to avoid using fragrance on the day of their appointment, turn essential oil diffusers off as well as wi-fi routers.

Unfortunately, many faced refusals, explaining that the dental staff rarely accommodated them and did not show much empathy. For instance, a participant reported being rejected by the dental staff: "don't bother coming, no, no, we can't deal with you! I'm sorry our clients have perfume we can't

do anything". Those challenges and rejections generated anxiety and distress among the participants.

*Interviewer: So, when you call and you ask them to accommodate, exactly what do you ask for?*

*Participant: I just said that I have chemical sensitivity, I need it to be perfume-free, and shampoo that smells free and scent-free and they were like I am sorry we can't do that.*

*Interviewer: okay and that's all you ask for?*

*Participant: That's how I start! I say that I have a problem, can you be scent-free no cream on your hand. I didn't ask a lot they told me right away, I didn't get very far. We can't deal with you sorry our office is not equipped to deal with you [...] [Int. 1]*

Eventually, almost all participants opted for holistic dentists, also known as naturopaths. This choice did not resolve all issues, though, especially concerning wireless communications. A participant explained that holistic dentists would switch off the wi-fi and all cordless devices whenever possible, but that it was more difficult recently as all the patients would carry cellphones and expect access to wi-fi networks. Participants also explained that the clinics were increasingly dependent on wireless devices such as payment machines, cellphones, Bluetooth operated keyboards, and computer mouse.

*Participant: Je demandais au dentiste d'éteindre le wifi puis de pas avoir leur iPhone dans leur poche quand ils travaillaient avec moi. Ils collaboraient mais à un moment donné veut-pas. Le centre commercial dans lequel eux étaient, ils ont mis des antennes sans fil. Puis, sinon c'était les clients dans la salle d'attente qui utilisent leur cellulaire puis dans le fond y'a juste un mur, mur de gypse entre la salle d'attente et la salle de traitement. J'étais à proximité des émetteurs tout le temps. Puis c'est mon dentiste actuel, dentiste holistique c'est ça lui au début il n'avait pas de problème, il éteignait tout ce qui était sans fil mais au fil du temps de 2010 à maintenant, tous les clients passent tout leur temps sur leur téléphone sur place. Les machines de paiement direct dans les cliniques ils sont sans fil donc ils ont besoin du Bluetooth ou du wifi pour fonctionner. Les appareils de dentisterie ben, si on veut le cap de communication filaire là ça coûte plus cher parce que c'est des options fait que les dentistes les prennent pas ou bien même les fabricants y'offrent pas la machine avec les connections réseaux. Donc c'est obligatoirement wifi pour fonctionner. Fait que mon dentiste il m'accommodait. Il m'accommode plus ben fait que là pour moi c'est compliqué là. [...] [Int.12]*

Although few participants faced difficulties when requesting accommodation from holistic dentists, most were satisfied because these practitioners were aware of environmental sensitivities and tried to adjust accordingly. For instance, one participant lauded her holistic dentist for avoiding scented products on herself and having her clinic tested for electromagnetic fields, thus assuring people that the clinic was a safe environment.

*Participant : Elle avait fait évaluer les champs électromagnétiques de sa clinique. Alors c'était déjà un environnement vraiment bien. Puis en étant une dentiste naturelle, ses vêtements aussi n'avait pas de parfum. Donc ça c'est très très très difficile pour une personne qui est chimico-intolérante quand il y a de la lessive ordinaire sur le dentiste. Interviewer: Donc vous n'avez pas eu besoin de faire des demandes de changement avec elle?*

*Participant: Non, pas avec elle. Alors c'est pour ça que je l'ai choisi. [...] [Int.2]*

#### **5.4.4 During waiting time at the dental clinic**

According to the participants, the waiting time in dental clinics may take longer than expected, even with a scheduled appointment. This situation was a challenge for them because they explained that they could bear exposures for two to five minutes, for example, but not hours of exposure to incitants. Their exposure in the waiting room depended on several factors: the time they had to wait, the number of patients and their proximity in the room, and the use of wireless electronic devices in the clinic.

The participants explained that the intensity of their adverse effects was directly proportional to the length of exposure to incitants. Consequently, the longer they would wait at the clinic, the longer they would get exposed and suffer from it. Participants explained that wearing personal protective equipment reduced or delayed the effects of exposure but never prevented them entirely. To monitor their exposure, several participants carried an electromagnetic radiation tester to the clinic to measure the strength of the magnetic field. The measuring unit of the device was millivolts per meter, and participants considered below 15mv/m bearable.

*Participant: My device measure millivolts per meter and if it is 20mv, 20 can be bad. Below 15mv, I am very happy [...] [Int.7]*

*The last time I have seen her, I went to her office when I had an appointment, and I brought my meters [tester] with me. I showed her how high the magnetic fields are from her chair [...] [Int.6]*

To avoid these issues, some participants waited outside of the clinic until their turn. They avoided the elevator in the building and tried to remain far from people in the clinic; some scheduled early morning appointments and asked to be the first patient to have the waiting area empty and reduce contact with other people. It needs to be noted that waiting outside of the clinic was not an easy task for most patients, especially during winter.

*Participant: When you have the elevator, you get out of the car you go into the elevator, you have people with the perfume in the elevator, so, you are trying to avoid that with mask and nose plug and everything else, so that's a problem. Then you get up into the office, there are all these other people so you are trying to find a place as far away as possible or you stand in the corridor if there is nobody else walking into the corridor so then you get called into the office. I have no idea how to deal with that now because I go into convulsion more now than before. That's what it used to be. Right now, unless I get a lot better, I can't go anywhere. [...] [Int. 1]*

*Je téléphone, j'y vais à la dernière minute. Pis quand j'arrive, tout de suite je rentre pour me faire le traitement pis je repars le plus vite possible. [...] [Int.11]*

#### **5.4.5 During dental treatment**

The participants identified certain dental materials and instruments that were harmful to their health, such as local anesthesia, amalgam fillings, metal base prostheses, radiographic machines, and dental polishing paste. Most mentioned to their dentist being sensitive to local anesthesia, especially when it contained epinephrine. With respect to amalgam fillings, participants reiterated their sensitivity to this material and insisted on having them removed and replaced by composites. They explained that these procedures created financial and psychological stresses due to the repetition of dental visits, but they considered that it was worth it as the "cloudiness in the brain, headache and dizziness" slowly disappeared after.

As we briefly mentioned before (section 6.4.1), the participants stated that the method of amalgam removal needed to respect the SMART protocol, with the following steps: 1- They would rinse their mouth with a slurry of charcoal absorbent and swallow it before the procedure (unless medically stated otherwise). 2- The dentist would install an amalgam separator to collect the mercury amalgam waste. 3-The dental room should be well ventilated with a high-volume air filtration system. 4-The windows should be open if possible. 5-Everyone in the room, including them, the dental assistants, and the dentist, would wear protective gowns. 6- The dentist and dental assistants would also wear a face shield and properly sealed mask providing oxygen.

*Participant : Ok. Ben premièrement, dès que j'ai compris que j'avais ça j'ai recontacté mon dentiste que ça faisait 25 ans que j'avais. C'est lui qui m'a suggéré peut-être qu'il y avait de l'activité électrique dans ma bouche. Mais il n'était pas très ouvert. Il ne m'a pas accommodé... En tout cas. Je l'ai laissé là puis je suis passé à un autre type de dentiste. Un dentiste holistique. J'ai fait de téléphone pour m'assurer qu'il faisait le protocole de l'AIMOT. Ça c'est l'association internationale... en tout cas c'est une association de dentiste holistique qui font un protocole sécuritaire pour le retrait des amalgames.*

*[Int.2]*

The participants also wanted to remove the metallic materials other than amalgams. For instance, one explained that he requested his dentist to remove a dental post from his canine tooth due to a medically unexplained paralysis and swelling on the right side of his face. This procedure was not successful, though, as the side-effects subsided after the post removal.

*Participant : Là il s'est produit un phénomène, j'ai commencé à avoir des paresthésies du côté droit du visage avec un engourdissement dans le côté de mon oeil, une grosse veine verte. Un engourdissement dans le côté de mon oeil qui descendait jusque dans le côté du nez. Ça allait jusque vis-à-vis*

*Interviewer: C'est à cause de l'infection?*

*Participant : Mettons qu'on a pas fait le lien tout de suite. Au fil du temps on a fini par penser. Le pivot y'est en or et en argent. Ok, et il mesure un centimètre. C'est le quart d'une onde euh... C'est la même dimension qu'une antenne de téléphone cellulaire, c'est à peu près les mêmes matériaux à ce moment là. Pis euh, pis comme je suis électro-sensible on s'est dit ben ça y est, peut être que je réagis à ça tser? ---- On a retiré ce pivot-là vue que ça faisait un an que j'avais une blessure qui guérissait pas. Pis aussitôt qu'on a retiré ça, le surlendemain c'était cicatrisé. [...] [Int.12]*

Another difficulty faced by some participants was replacing crown and bridges with a more biocompatible material such as zirconia; due to their high cost, very few could replace it, and others opted for dental extraction.

*Participant : Là on avait, euh qu'est-ce qu'on avait mis? Un pivot en zircon. Les pivots en zircon. Pis on avait juste fermé la dent temporairement parce que [là il manquait (l'argent)] Ça avait coûté 2-3 milles pour faire ça. Pis ça a coûté quasiment autant pour tout enlever pis refaire une dent temporaire. [...] [Int.12]*

Few participants were also concerned by the radiographic machines, especially those based on digital technology, which would generate adverse effects. Consequently, most participants refused radiographs, considering that the radiographs' adverse effects would be worse than their benefits. Participants deplored dentists' lack of understanding and support. For instance, one participant described her experience with a dentist that convinced her to take a radiograph, arguing that the exposure was minimal and harmless. She accepted but regretted it afterward because it caused blisters on her legs "as if she got burned."

*Participants: Numerique is awful. It is worst than "analogique." I just have to give you an idea! The cable for my television is analogique. I could watch television for an hour, or so it wasn't too bad then after that I have to close it because I was getting hot and cold and dizzy and I wasn't feeling well. I get all jittery all my nervous system gets all jittery, and I take a glass of water, and I go for a walk, and I am okay. But they changed it because they don't have allergic, so they have numérique WELL! I told them I think I have a problem with that and they were like "oh! oh! Let's try!". I said, "okay, let's try it. So, she wanted to take an x-ray, and she said," Oh! It is numérique you won't react to this" So again I said "okay! Let's try it; maybe I won't react as much" well, I did. My legs became the same thing. The entire leg underneath up to the ankle full of blisters as if I was burned. [...] [Int.3]*

Additionally, the participants requested the hygienist to skip the dental polishing after dental cleanings, as the prophy paste contained flavoring ingredients such as cinnamon and mint.

#### **5.4.6 Financial constraints**

Many participants mentioned that financial constraints impeded their access to dental care. Only two had a job (only one worked full-time), whereas the others had to stop working due to environmental sensitivities. Most used to work before developing environmental sensitivities and thus received a disability or a retirement pension. Besides, one person was on social assistance. It needs to be noted that the participants who received the Quebec pension under the disability act because of depression and not environmental sensitivities, which is still not fully recognized as a disability in Quebec.

Participants without any dental insurance had to pay treatment out of their pockets and thus faced financial challenges. For instance, one participant explained that she could not afford routine dental care, such as dental cleaning every 6 to 12 months. Another also explained how he ended up in debt for dental treatments.

*Participant : Toutes mes dents ont été percées, remplies avec des médicaments et refermées avec des plombages pis des couronnes en stainless. C'était dans les années 75, ça commencé là pis après ça ben à un moment donné ces dents-là ont tombé, ça été remplacé par d'autres dents naturellement qui ont pas toughé tout de suite et ont commencé à s'effriter et à perdre des morceaux. Donc ils ont percé, rempli avec des plombages gris euh à tous les ans, y'avait toujours des plombages à faire. Même à 20 ans! À 20 ans, fallait que j'emprunte de l'argent pour être capable de dépenser 2000\$ par année en plomage pour refaire mes dents. [...] [Int.12]*

One participant was on social assistance and thus benefitted from public dental coverage. She nevertheless complained about the limited selection of dental materials: the government insurance only covered amalgam fillings and did not allow people to replace them with composite fillings (for posterior teeth) and pay the difference. The only solution for her would then pay the entire cost out of her pocket. Despite the financial barrier, the participant paid the entire dental fees by using a credit card, which caused excessive debt leading to bankruptcy. However, the participant overcame by opting for Dépôt volontaire; a service provider that uniquely facilitates Quebec residents to pay off their debt by negotiating with their creditors.

*Participant : Je veux payer la différence entre ce que ça vous coûte, entre l'amalgame et le composite. Alors ils m'ont dit non on ne peut pas faire ça. Alors voilà, j'ai dû payer de ma poche, avec une carte de crédit et puis j'ai fait retirer les couronnes aussi, toujours à crédit. Et puis j'avais déjà fait une faillite en 2006 parce que j'étais déjà malade et au moment où on se parle je pourrais faire une faillite une deuxième fois, mais je suis au dépôt volontaire.*

*Interviewer : Ok. Puis, euh*

*Participant : Dépôt volontaire c'est qu'au lieu de faire faillite, c'est uniquement au Québec que c'est possible. C'est qu'on peut signer un contrat comme de quoi à chaque mois on donne un petit montant. [...] [Int.2]*

A few participants had private insurance plans through their previous job or their spouse's employment. Even though they were relatively satisfied with their coverage, they felt it was insufficient as they could not exceed a maximum amount of 1000\$/ year. They also highlighted the burden of their insurance premiums to maintain dental coverage. They mentioned that the services were still not free after paying the premiums; they had to cover 20% of their bill. Although the Canada Revenue Agency (CRA) return some money after tax-filing, participants felt they paid a hefty amount.

## **5.5 Mitigation strategies recommended by participants**

Participants provided certain valuable recommendations that they thought could make a difference with their access to dental care.

### **5.5.1 Effective strategies for environmental sensitivities**

Participants recommended that dentists avoid using scented products at least the day of their appointment and adopt chemical-free cleaning approaches. They explained that the ideal method would be a complete cessation of scented products; however, they felt it was an unrealistic demand. They also suggested having a separate waiting room for people with environmental sensitivities to avoid triggering symptoms as often the waiting time is extended. Additionally, participants emphasized maintaining good indoor air quality as much as possible as they explained this method would prevent people from inhaling toxic substances.

*Participant: The person who will come will not have to wear any perfume or put any perfumed deodorant just before they arrive. Their clothes will have to be washed with a -- - I hate to say this, it is a lot to ask but -- use a detergent that does not have any perfume. The drier like Bounce or liquid little perfume material used in drier also would have to stop completely. Unfortunately, also people who smoke, even if they do not smoke for a few hours before they arrive, they emit cigarette smoke, so I know it is difficult. [...] [Int.4]*

Regarding electromagnetic hypersensitivities specifically, participants recommended that the clinicians avoid wireless connections and devices by implementing a wireline system for all devices. They reasoned that this technique is the safest method for preventing harmful effects. They also thought that new clinics should be located in non-commercial areas and thoroughly evaluated for electromagnetic field by experts.

*Participant : Puis faire évaluer la clinique par un--- "expertise 3E" qui est un évaluateur de champs électromagnétique. Parce qu'il peut y avoir des problèmes au niveau de l'électricité de la bâtisse. Il peut y avoir des sources qui viennent de l'extérieur, qui rentrent dans la clinique alors ils vont dire "bon ben vous allez peindre ce mur-là avec une peinture blindante ou ils vont donner tous les correctifs." [...] [Int.2]*

Furthermore, participants believed that dentists should modify some of their treatment modalities; amalgam fillings, in particular, should be banned and replaced by more biocompatible materials such as a composite filling. Concerning complete and partial dentures, most participants recommended non-metallic materials to avoid symptoms like tinnitus and headaches.

With respect to financial issues, most participants recommended an affordable cost for oral health care. Participants benefiting from social assistance also suggested having composite filling for posterior teeth included in their coverage.

Lastly, some participants emphasized increasing dentists' awareness by introducing lectures on environmental sensitivities in dental and post-graduate education; they wished dentists could become more knowledgeable and more empathetic towards their situation and better respond to their specific needs.

## Chapter 6: Discussion

### **6.1 Preliminary reflections**

There are two different perspectives concerning environmental sensitivities: the perspectives of the people living with environmental sensitivities or their allies and the views of people, including medical practitioners, who doubt the existence of environmental sensitivities. Regarding the first perspective, people with environmental sensitivities are suffering daily and fighting on many fronts; their most crucial standpoint for recognizing multiple chemical sensitivities and electromagnetic hypersensitivities as real conditions is essential to them. They fight for access to care, a safer environment and do not want to be considered as people with mental health issues, arguing that the challenges they face are real and require solutions [4]. In parallel, many health professionals seem skeptical about environmental sensitivities; some doubt it is a real condition; others relate environmental sensitivities to mental illness or depression [7, 65]. For instance, a study conducted in United States showed that out of 90 physicians, half considered multiple chemical sensitivities as a psychological condition, and only 6% knew about environmental sensitivities [110]. Due to this, medical practitioners may not take patients with environmental sensitivities very seriously and may be reluctant to accommodate them [9, 10].

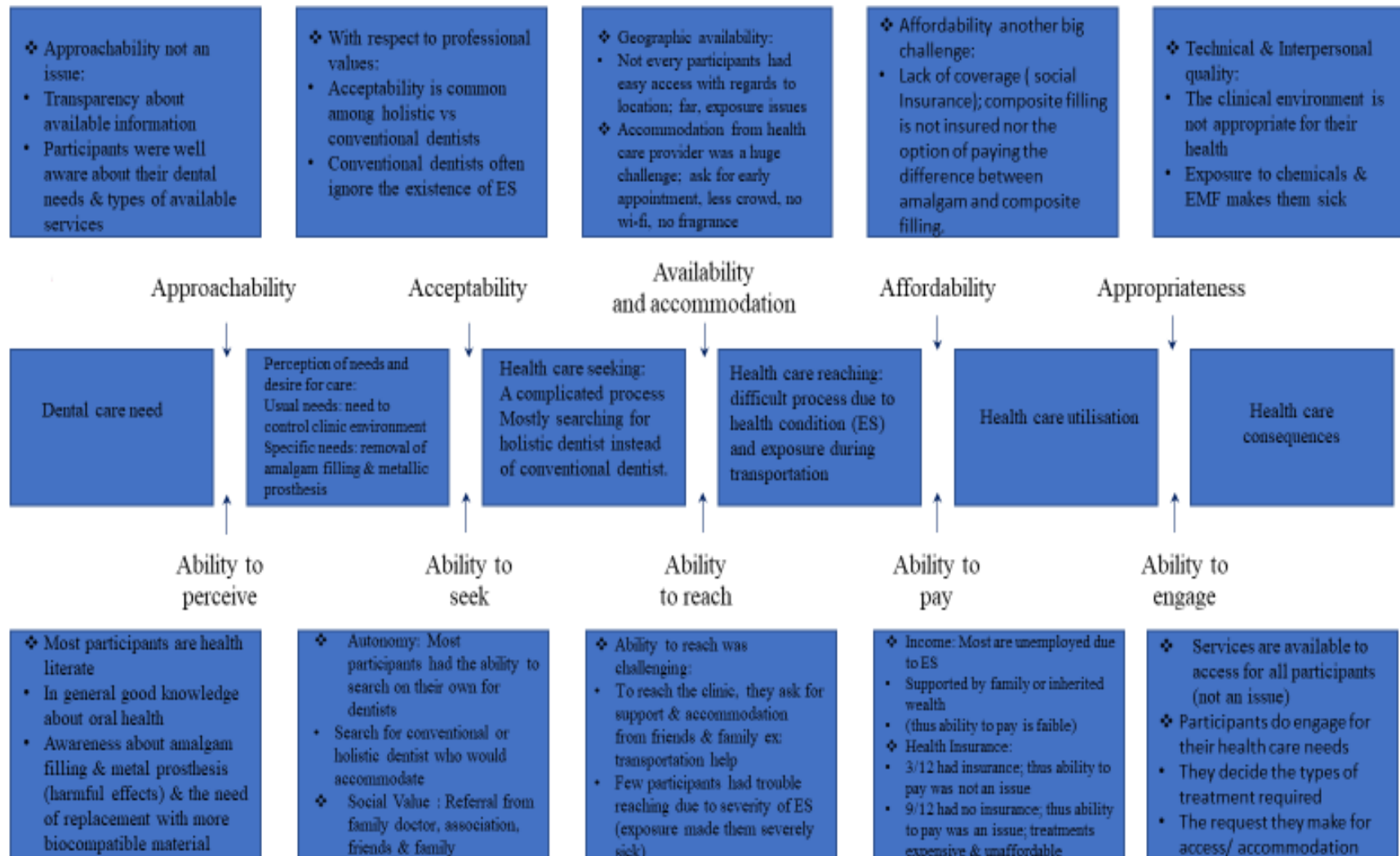
The position of our team on this controversial issue is clear. First, our community partners consider environmental sensitivities as a real condition; they support people with environmental sensitivities to have a good quality of life and defend their rights, especially their health rights. As stated by the World Health Organization, "Quality of care is a key component of the right to health, and the route to equity and dignity" [111]. Dr. Bedos and I are allied with these organizations. Even though we acknowledge the lack of scientific evidence on the pathological processes related to environmental sensitivities, we discovered with this project that people with environmental sensitivities suffer dramatically and struggle to access care. We thus support their fight for recognition and their rights to health and access to care.

## **6.2 Summary of findings**

In the previous section, we documented two important challenges faced by people living with environmental sensitivities: exposure to the surroundings (multiple chemicals & electromagnetic fields) and access to dental care. Concerning the first point, we revealed that people get sick when exposed to the outside world and thus take refuge in their homes, a strategy that has been documented in the literature [57]. Gibson et al. described how environmentally sensitive individuals have "no life anymore," they are "homebound," and if they managed to leave for the essential task, they get sick and nauseous for two to three days before getting normal [57].

Because health care facilities are part of this external world that contains incitants, access to care constitutes an important challenge for people living with environmental sensitivities. For instance, the presence of various chemicals along their route or in the hospital vicinity worsens their symptoms [112]. It thus hinders their access to care and may cause extreme distress [7]. Dental care facilities are also part of the external world, and as our research shows, accessing them is extremely difficult for people living with environmental sensitivities. Figure 4, based on Levesque's model [74], summarizes their dental care pathway and describes how it is influenced by the accessibility of the dental care system and the ability of the people living with environmental sensitivities.

Figure 4. Research findings presented according to Levesque's model of access



### **Approachability & ability to perceive**

Approachability is not a major issue for people with environmental sensitivities, as they can relatively easily identify available dental clinics. The clinics are usually transparent about available services and treatments and, as a result, approachable. Besides, with respect to their ability to perceive, most participants were health literate with adequate knowledge about oral health and dental needs. Similarly, Chircop and Keddy found that people with environmental sensitivities were educated and knowledgeable about their illness with realistic health concerns [112]. More specifically, most participants were knowledgeable about the effects of metallic material in their mouth, such as amalgam and prostheses, and the advantages of having them replaced with more biocompatible materials.

### **Acceptability & ability to seek**

In participants' experience, holistic dentists seemed to accept their requests and their specific needs better than conventional clinicians. Conventional dentists seemed not aware of environmental sensitivities and the importance of considering environmental factors when opening or managing their clinics. On the opposite, many holistic dentists tried to render their clinical environment acceptable by adopting certain measures and techniques (scent-free environment, reading electromagnetic frequencies, temporary turning off wi-fi, SMART technique for amalgam removal). Gibson et al. also found that a common barrier towards access to care was to find a physician who would understand, diagnose, and treat their condition [9]. To enhance acceptability, these authors thus recommended providing appropriate professionals with training regarding multiple chemical sensitivities and electromagnetic hypersensitivities [9].

Participants showed their ability to seek a dentist, whether holistic or conventional, but most were inclined towards holistic dentists due to their ability to accommodate. In this search, participants received the support of various people, such as their family physician, members of associations supporting people with environmental sensitivities, as well as family and friends, to seek dental care.

### **Availability - accommodation & ability to reach**

With respect to geographic availability, participants explained that, even though there were clinics within their vicinity, they sometimes had to consult in a distant location, which resulted in a considerable amount of challenges: extra travel time, transportation issues, and difficulties to find a companion willing to travel to the dental clinic. In sum, people's ability to reach was limited by two primary reasons: 1- the disability caused by environmental sensitivities, which was so severe that they did not feel healthy enough to leave their home. 2- the difficulty to find friends or family members for transportation and visit.

With respect to accommodation, participants faced significant challenges due to the struggle associated with finding a dentist willing to accommodate their needs. This issue resulted in many barriers to access dental care, such as delayed treatment or no treatment at all. Similarly, Gibson et al. emphasized that health care providers need to create a safe environment for people with environmental sensitivities by accommodating their needs [9, 57].

### **Affordability & ability to pay**

Affordability is a significant issue for people living with environmental sensitivities because of a lack of dental coverage: most of the research participants had no dental coverage, only one benefitted from the public dental program for people on social assistance. This program, though, has limitations, as people cannot have composite filling on posterior teeth. Furthermore, people do not have the liberty to pay the difference between composite and amalgam fillings, leaving them with two possible choices; either refuse the treatments or pay for composite fillings. Unfortunately, the ability to pay for people with environmental sensitivities is weak; most are unemployed due to environmental sensitivities and supported by inherited wealth or family aid. To overcome this, few participants took loans and had debts.

### **Appropriateness & ability to engage**

Levesque et al. stated that appropriateness represents “the fit between the service and clients needs” [74]. However, with regards to people suffering from environmental sensitivities, the fit is either weak or non-existent because the clinical environment and services at conventional dentists

are mostly unsafe. This is why most participants approached holistic dentists. Besides, participants seemed able to engage in their healthcare needs, knowing what treatment to avail, and discussing with dentists to explain their specific needs.

### **6.3 Contribution of our study**

To the best of our knowledge, we conducted the first study focusing on people with environmental sensitivities regarding access to dental care. Previous studies have covered other important aspects pertaining to environmental sensitivities; for instance, Gibson et al. [8] have reported many issues related to their situation, in particular access to medical health care and the community [8, 23, 57]. Other authors focused on different facets of environmental sensitivities: clinical characteristics, prevalence, lack of recognition, and marginalization of this community.

With respect to access to medical care, previous studies had described issues similar to what we highlighted, such as the inability to find a health care provider who would understand environmental sensitivities and the lack of accessibility of health care facilities due to exposure to chemicals and electromagnetic waves. This said, previous studies had not described as we did people's care pathway from the identification of a need to the end of the care episode.

### **6.4 Limitations of this study**

#### **Limitation #1**

We conducted the study in the province of Quebec, and therefore, our findings are embedded in its specific social, political, cultural, economic, and environmental context. Some aspects of Quebec's dental care system and its regulation, for instance, do not apply in other provinces and countries. Even though our findings are not generalizable, they may be transferable to other contexts. It is up to the readers to appreciate in which ways and to what extent our findings may apply to where they live.

## **Limitation #2**

The second limitation is related to different types of environmental sensitivities. I stated in the literature review that environmental sensitivities is an umbrella term that includes many kinds of sensitivities, such as electromagnetic hypersensitivities, multiple chemical sensitivities, noise sensitivities, and light sensitivities. However, this thesis focuses only on multiple chemical sensitivities and electromagnetic hypersensitivities. Further studies are required to learn about the effect of noise sensitivities and light sensitivities on access to dental care.

## **Limitation #3**

The method of the interview was the third limitation. Due to the participants' health condition, I interviewed them over the phone to avoid exposure to incitants. Although the participants felt comfortable talking over the phone and describing their experiences concerning access to dental care, I felt that face-to-face interviews could have enhanced my understanding and provided deeper data. The benefits of face-to-face interviews are, for instance, visual assistance with body language and facial expression, which can prevent misunderstandings during an interview.

## **6.5 Strengths of this study**

One of this study's strengths is related to our methodology. Our qualitative descriptive approach was very powerful to explore the health-related experiences of people who are marginalized and neglected. Our participatory approach was another strength; the integration of people affected by environmental sensitivities into the team provided us with exceptional insight and knowledge. Our partners' deep involvement thus reinforced the quality of this study.

## **6.6 Knowledge translation plan**

The findings of this research as well as our recommendations will be shared with the Ordre des dentistes du Québec to improve access to dental care for people affected by environmental sensitivities. We also plan to share the results with the McGill Faculty of Dentistry with the help

and guidance of Dr. Christophe Bedos, with the goal of improving the undergraduate curriculum. Lastly, we expect to publish our findings in a peer-reviewed journal for wider dissemination of the knowledge we produced [113].

## **6.7 Recommended solutions**

Our findings demonstrate that people with environmental sensitivities face many challenges, whether linked to environmental sensitivities or access to care. The following table (Table 5) summarizes our recommendation inspired by participants' advice. We categorized participants' challenges and associated recommendations according to Levesque et al.'s framework on access to care; as indicated in Table 6, these recommendations are intended to address the government, the ODQ, dentists, and dental educators.

**Table 5. Recommendations to enhance access to dental care for people with environmental sensitivities**

<b>Challenges faced by participants concerning</b>	<b>Recommended Solutions</b>	<b>Recommendation intended for the followings</b>
<b>1. Availability &amp; Accommodation</b>	<b>-Provide early morning appointments</b> To prevent exposure to multiple people in the clinic.	-Dentists, ODQ, Dental educators
	<b>-Provide the option of Teledentistry (E-dent)</b> Oral teleconsultation services should be widely available, especially for people with disabilities.	-Dentists, ODQ, Dental educators, Government
	<b>-Provide the option of mobile clinics for urgent care</b>	-Dentists, ODQ, Dental educators, Government

	Dental professionals should be trained and equipped to provide scent-free domiciliary dental care to environmentally sensitive individuals.	
<b>2. Affordability</b>	Cover the cost of composite fillings (posterior teeth) as part of the RAMQ insurance program for people on social assistance.	-Government
<b>3. Appropriateness</b>	<p><b>-Establish a scent-free policy in dental offices.</b> Clinics should make efforts to be scent-free from perfume, scented oil diffuser, scented cleaning products.</p> <p>Visitors and patients should be notified of such scent-free policies. There should also be signs at the clinic stating “scent-free zone.”</p> <p><b>-Dental clinics should be transparent about clinic renovations</b> Clinics should inform patients with environmental sensitivities about any recent renovations (during the renovations, they should use the least toxic products available).</p> <p><b>-Dental clinics should have a wire line set-up</b></p>	<p>-Dentists, ODQ, Government</p> <p>-Dentists</p> <p>-Dentists</p> <p>-Dentists, ODQ, Dental educators</p>

	<p>Clinics should have an easy switch to wire line set-up (temporary cessation of wi-fi).</p> <p><b>-Dental clinics should have a policy on cell phone use</b> Clinics should establish days when cellphones would be switched off.</p> <p><b>-Dental clinics should implement changes in their design</b> Clinics could provide a separate waiting room for people with environmental sensitivities.</p> <p><b>-Dental clinics should carefully use amalgam fillings &amp; provide metallic prosthesis</b> Dental care providers should be educated on the side-effects of metallic dental materials on people with environmental sensitivities.</p> <p><b>-Dental clinics should carefully use anesthesia (local or general) on people with environmental sensitivities</b> Dental care providers should be aware of the side-effects of anesthesia on people with environmental sensitivities.</p> <p><b>- Dental professionals should receive adequate training on environmental sensitivities</b></p>	<p>-Dentists, ODQ, Dental educators</p> <p>-Dentists, ODQ, Dental educators</p> <p>-Dentists, Dental educators</p> <p>-Dentists, ODQ, Dental educators</p> <p>-Dentists, ODQ, Dental educators</p>
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#### **4. Acceptability**

Dental educators should increase future clinicians' sensitivity towards people with environmental sensitivities

-Dentists, ODQ, Dental educators

## **Chapter 7: Conclusion**

This study shows the perspectives and experiences of people with environmental sensitivities regarding access to dental care. Although there are studies describing the barriers to access medical health care for people with environmental sensitivities, our study seems to be the first in our field. We learned that: (1) People with environmental sensitivities face major and numerous challenges to access dental service; (2) Dentists seem to be poorly prepared to welcome them, and due to a lack of awareness, may not be able or willing to accommodate. (3) This reduced accessibility to dental care may lead to distress among people with environmental sensitivities. We also proposed several solutions to improve their access to dental services. Our recommendations are targeted towards several governmental and professional institutions who need to listen to this marginalized and poorly heard group of citizens.

We are thus calling the government to support people with environmental sensitivities, a forgotten population that faces tremendous daily challenges, including access to dental services. In collaboration with professional orders, the government should provide them with affordable and appropriate dental services that comprise teledentistry and mobile services. It is important to remember that Canada signed the UN Convention on the Rights of Persons with Disabilities, which stipulates that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” [114]. Besides, dental faculties should train future and current professionals on environmental sensitivities and ways to serve this population best. Researchers should also be part of this effort and conduct studies on this poorly explored subject. One pertinent research avenue could investigate dentists' perspectives on this issue and their willingness to treat people with environmental sensitivities.

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## Appendices

### Appendice A: Consent form



Faculty of Dentistry  
McGill University,  
2001 Ave McGill College,  
Montreal, QC H3A 1G1

### **INFORMATION AND CONSENT FORM**

#### ***Title of Research Project:***

Perspectives of people affected by environmental sensitivities concerning access to dental care, oral health and illness

#### ***Researchers:***

##### **Principal Investigator:**

Dr. Christophe Bedos, Associate Professor, McGill University, Faculty of Dentistry, Division of Oral Health and Society

##### **Student Investigator:**

Dr. Farah Ahmed, McGill University, Faculty of Dentistry, Division of Oral Health and Society

##### **Advisory Committee:**

Ms. Jacinthe Ouellet

(La Fondation Air & Vie)

Ms. Rohini Peris & Mr. Michel Gaudet

(Association pour la santé environnementale du Québec - Environmental Health Association of Québec)

Ms. Hélène Vadeboncoeur

(Rassemblement ÉlectroSensibilité Québec)

***Introduction:***

We invite you to be part of our research. Please read the consent form completely and carefully before signing it. The form describes the purpose of this study, the nature of your participation and your rights. If you have any additional questions, please discuss with one of our researchers. Your participation in this study is voluntary: you can refuse to participate or, withdraw at any time without any consequences.

***Purpose of the research:***

We want to better understand the perspectives of people with environmental sensitivities concerning access to dental care, oral health, and illness.

***Study procedures:***

Your participation is voluntary. If you agree, we will ask you to take part in a face-to-face, semi-structured interview with Farah Ahmed. This interview will take place either at your house or in a public place of your preference, as long as it is quiet and permits us to be discrete. The interview will be conducted in English or French according to your preference. It will last approximately one hour. If the discussion is not finished after an hour, we may invite you for a second interview.

The interviewer, Ms. Farah Ahmed, will ask simple questions about your illness, your current and past experiences regarding this illness, and your access to dental care services. The interview will be audiotaped with your permission. Overall, we expect to conduct between 10 and 15 interviews with different people. If you opt out of the audio recording, you can still take part in the study and the interviewer will document the interview with hand-written notes or by typing on a computer.

During the interview, if you feel the need to stop the discussion, please feel free to inform the interviewer. You can take a break at any point during the interview.

***Possible risks:***

There is no particular risk involved in this study. However, it is possible that participants might face some emotional distress during the interview. If this happens to you, you can opt not to answer the questions that you are not comfortable with. You can take a break to overcome the emotional stress and once you feel the need to resume back, we will continue with the interview. If you agree to conduct the interview in a public place, you have the choice to bring your friend or relative for moral support and to help you overcome any emotional distress. You will also have all rights to discontinue the interview and withdraw from the study without any consequences.

***Possible benefits:***

There is no direct benefit to you for taking part in this study. However, we hope that this study will help the dental professionals to better understand the situation of people with environmental sensitivities. Ultimately, our goal is to promote access to the dental care system.

***Confidentiality:***

The information that you will provide will remain confidential. Your name will be number coded to protect your identity. All documents will be stored on Farah's laptop and backed-up on OneDrive account with password-protection, and only Dr. Christophe Bedos, her supervisor, and professor at McGill University will have access to those files. The stored data will be destroyed after seven years as per University policy. All the paper documents such as consent forms will be stored in a locked filing cabinet at McGill University. They will be accessible only to Dr. Christophe Bedos. The findings of this study will be published in scientific journals and presented at conferences; they will also be used in dental schools to better prepare future and current dental professionals. You might be quoted in these documents; however, we will make sure that these quotations will remain anonymous. Consequently, the readers will not be able to identify you or the people that you may mention during the interview. Your name will not be mentioned in the paper nor any information that would permit the readers to recognize individual's identity.

A representative of the McGill Institutional Review Board, or a person designated by this Board, may access the study data to verify the ethical conduct of this study.

***Compensation:***

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

***Contact information for questions about the study:***

Dr. Farah Ahmed: MSc Dental Science Student, McGill University, Faculty of Dentistry, 2001 Ave McGill College, Montreal, QC, H3A 1G1. Tel: 514-999-1087.

Email: [farah.ahmed@mail.mcgill.ca](mailto:farah.ahmed@mail.mcgill.ca)

Dr. Christophe Bedos: Associate Professor, McGill University, Faculty of Dentistry, 2001 Ave McGill College, Montreal, QC, H3A 1G1. Tel: 514-398-7203 ext.# 0129

Email: [christophe.bedos@mcgill.ca](mailto:christophe.bedos@mcgill.ca)

***Contact information for questions about rights of research participants:***

If you have any questions or concerns regarding your rights or welfare as a participant in this study, you can contact:

Ms. Ilde Lepore: Ethics Officer for the McGill Institutional Review Board, McGill University, Faculty of Medicine, McIntyre Building, #633-3655 Promenade Sir William Osler, Montreal, QC H3G 1Y6. Tel: (514) 398-8302. Email: [ilde.lepore@mcgill.ca](mailto:ilde.lepore@mcgill.ca)

**CONSENT:**

Please tick your choice of yes or no next to the question.

I agree to be audio-recorded during the interview    ☐ YES    \_\_\_\_\_    ☐ NO    \_\_\_\_\_

*By signing this form, I agree that; I have read the information provided in this consent form and that I am volunteering for this project. I understand that I can stop the interview at any time or take a break in between. I understand that the transcribed interview may be used as described above and that I don't expect to receive any benefit or payment for my participation. I am aware that I can ask any questions I might have during the interview, and that I am free to contact the researcher with any questions I may have in the future. I understand that I am free to withdraw from this study at any time.*

*I have been informed that my name will not be mentioned in any publications that are in association with this study. I am not giving up any of my legal rights by signing this consent form.*

Name of the participant: ..... Date: .....

Signature of the participant: .....

Person who obtained consent: ..... Date: .....

Signature of person who obtained consent: .....

## Appendix B: Interview guide

The interview guide is built with the help of access to health care framework formed by Levesque et al. [115] and McGill Illness Narrative Interview (MINI) by Danielle Groleau et al [116].

The interview will consist of open-ended questions that will be repeated in the same sequence with each participant individually.

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### *Introduction*

*I would like to thank you for your contribution to this project by participating in this interview regarding access to dental care services. Your point of view matter to us and will help us find solutions to your problems and improve access to dental care services.*

### **1-Introduction**

a-How are you?

b-Could you tell me a little bit about yourself?

### **2- Experiences addressing environmental sensitivities**

a- We would like to know more about your experience. Could you tell us when you realized you had (ES)? Probe: When, Where...

b- What type of ES do you have? One or both? And which one appeared first (if they have both)

c- When did you experience your environmental sensitivities for the first time?

d- What were the symptoms?

e- Followed by probes

f- Could you tell me what happened when you had your (ES)?

g- Followed by probes

h- How do you feel about it?

i- Did you go visit a physician about your illness?

Follow up: i- if yes, what did he/she say?

ii- did they diagnose you as ES?

Follow up: if not, why not?

- j- Could you please tell me what it means to live with ES?
- k- Probe

### **3-Experiences addressing dental problems**

- a- When did you experience your dental problem or difficulties for the first time?
- b- Could you tell me what happens?
- c- Followed by probes
- d- I would like to know more about your experience. Could you tell me when you realized you had (dental problem)?
- e- Could you tell me what happened when you had your (dental problem)?
- f- Followed by probes
- g- How do you feel about your experience concerning dental problems?
- h- Is there anything else you would like to add related to dental problems that you think is valuable for this interview?

### **4- Experiences addressing access to dental care services**

- a- Can you tell me your experience of dental care services since after being ES?
  - b- Have you been to a dentist since you become environmentally sensitive?
- Follow up: If not, why not?
- i-If yes, how many times?
  - ii-what were your reasons for those visits?
  - iii-When was the last time you visit the dentist?
  - iv-Can you tell me more about your experience at the clinic?
  - v-Follow up: What happened afterward?
  - vi-How far is the clinic from your place?
  - vii-Follow up: Why did you prefer going to that clinic precisely? Any particular reason?
  - viii-How long does it take to reach the clinic? (if they tried to reach the clinic)
  - ix- How do you feel about a visit to the dentist? Does it give you anxiety? If yes, why?
- c-What difficulties did you face trying to reach a clinic?
- Follow up: How did you feel about it

d-What were the difficulties you faced once you were at the clinic?

Follow up: What effect clinical environment had on you?

Follow up: How did you feel about it?

Follow up: do you think mobile-clinic that comes to your house will be a solution to your symptoms?

e-Did you have any treatments for your dental illness?

Follow up: If not then why not?

i-If yes, how was your experience?

ii- How many visits did it require to complete your treatment?

iii- What is your point of view regarding the number of visits to the dentist?

iv-Can you describe what happened after you were seen by a dentist?

v-Anything you would change?

vi-Did you have any reaction/allergy to any material used on you during or after treatment?

Follow up: if yes, did you inform the dentist about it? then what happens?

vii- Did you have a reaction to other products used on you during the treatment? If yes, please

state which one

Follow up: if yes, how bad was your reaction? What was the duration of reaction?

f-Can you tell me what problems you had faced accepting the dental care service?

(cultural, social, environmental factor had an impact?)

g-What is your perspective regarding the costs of dental care?

i-Do you have dental insurance? If yes, what kind private or government?

ii-Do you think it has any effect on your dental treatment?

iii- What are your suggestions to change or improve it?

h-Did you ever ask for specific accommodations regarding your needs as an ES at the clinic? If so, what was the answer?

i-What sorts of facilities do you think a dental clinic should have to ease your treatment keeping your illness (ES) in mind?

j-When you approached a dentist for treatment, what was your satisfaction level afterward?

k-Were your needs and demand fulfilled? Explain your answer, please

l-According to you, how could we improve the dental care system to satisfy your needs?

Follow up: What do you think is missing in the dental clinic that is necessary for your accommodation?

m-Is there anything you would like to add that you think is valuable to this interview?

*I would like to ask you a couple of questions about yourself that are a little bit more personal and I would like you to know that you do not have to answer any of these questions if you do not feel like answering.*

**5- In regard to Socio-demographic aspect:**

a-How old are you?

b-Where do you live?

c-What is your marital status?

d-Do you have kids?

e-What is your highest level of education?

f- Are you currently employed?

Follow-up: If yes, what do you do for a living?

If no: a. how long have you been unemployed?

b. why, if you don't mind me asking?

c. What are your plans for future?

d. Will you resume work or are you currently looking for a job?

## **Appendice C: Abbreviation**

1. MCS: Multiple chemical sensitivities
2. EHS: Electromagnetic hypersensitivities
3. ES: Environmental sensitivities
4. EMF: Electromagnetic field
5. MUPS: Medically unexplained physical symptoms
6. SRI: Sensitivity-related illnesses
7. IEI-EMF: Idiopathic environmental intolerance with attribution to electromagnetic field
8. RAMQ: Régie de l'assurance maladie du Québec
9. WHO : World Health Organisation
10. TMJ: Temporomandibular joint
11. MRI: Magnetic Resonance Imaging
12. ELF-MF: Extremely low-frequency magnetic fields
13. RF: Radiofrequency
14. MDD: Major depressive disorder
15. GAD: Generalized anxiety disorder
16. SMART: Safe Mercury Amalgam Removal Technique
17. PPE: Personal protective Equipment
18. CR: Computed Radiography
19. DR: Direct Radiography
20. CRA: Canada Revenue Agency
21. ODQ: Ordre des dentistes du Québec.