Access to dental services for people using a wheelchair

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DEDICATION

To my parents, for their continued love and support

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LIST OF ABREVATIONS

ICF	-International Classification of Functioning, Disability and Health
WHO	-World Health Organization
TMJ	-Temporomandibular Joint
RAPLIQ	-Regroupement des Activistes pour l'inclusion au Québec
ODQ	-Ordre des Dentistes du Québec
ACDQ	-Association des Chirurgiens Dentistes du Québec

ABSTRACT

Studies show that people with disabilities, including people using a wheelchair, have more untreated dental problems and tend to use dental services less than the rest of the population. Despite this discrepancy, the nature of these difficulties and the shape of their dental care pathways have not been studied. Consequently, this study was undertaken to address this gap, with the goal of better understanding the difficulties that people using a wheelchair experience in accessing dental services and to identify solutions to facilitate their access to quality dental services.

This research was structured to effectively study and advocate for possible solutions to this problem. It is based on a participative approach, culminating from the many partnerships we developed with people with physical disabilities, dental professionals, and dental educators. These partners formed an advisory committee that provided advice and direction during various stages of the project. Furthermore, we adopted a qualitative descriptive research design: a particularly appropriate way of exploring phenomena about which very little is known. Through a purposeful sampling strategy, we recruited 13 adults living in Montreal. All of the participants used a wheelchair because of various mobility impairments. We conducted a semi-structured individual interview with each of them and analyzed transcripts using an inductive thematic method.

The resulting interviews illustrate that people with physical disabilities face a wide range of barriers in accessing dental services. These difficulties were classified into 11 challenges faced throughout the dental care pathway. These challenges begin with the tasks of finding an accessible dentist, being accepted by the dentist as a patient, and organizing the appointment and its related transportation. After overcoming these challenges, people using a wheelchair can experience further difficulties entering the building, moving inside the clinic, and interacting with the staff. Moreover, additional difficulties occur during treatment sessions: transferring into the dental chair may be difficult or sometimes

impossible; once in the dental chair, people may experience physical pain, muscular spasms or other uncomfortable sensations. Time may also be an issue as sessions may last longer than expected. Finally, financial barriers related to the cost of dental treatment proved to be a recurrent concern.

Overall, our study conclusively shows that people using a wheelchair face discrimination in accessing dental services. The challenges we identified culminate in the creation of oral health inequalities as some people with physical disabilities eventually give up using these ill-adapted services. We firmly believe that it is the responsibility of any given society to remove the existing barriers that are faced by people using a wheelchair. Accordingly, this study provides a series of recommendations that will initiate and maintain this change. These recommendations are targeted at multiple sectors of society, including the government, the dental profession, dental faculties, and organizations that represent people with physical disabilities.

RÉSUMÉ

Les études montrent que les personnes à mobilité réduite ont plus souvent des problèmes dentaires non traités que le reste de la population; en outre, elles ont tendance à moins utiliser les services dentaires. Malgré cette situation problématique, on connait très mal le parcours thérapeutique des personnes à mobilité réduite et les difficultés que ces dernières rencontrent dans l'accès aux services. La présente étude a été entreprise pour remédier à cette lacune. Notre but était de mieux comprendre les difficultés que les personnes utilisant un fauteuil roulant rencontrent dans l'accès aux services de soins dentaires, et d'identifier des solutions pour remédier à leurs problèmes.

Cette recherche est basée sur une approche participative, et sur des partenariats avec des personnes à mobilité réduite, des professionnels dentaires et des éducateurs dentaires. Ces partenaires ont formé un comité consultatif qui nous a conseillé lors des différentes étapes du projet. En outre, nous avons adopté une méthodologie de recherche qualitative descriptive, approche qui est particulièrement appropriée pour explorer les phénomènes dont on sait très peu. Grâce à une stratégie d'échantillonnage ciblé, nous avons recruté 13 adultes vivant à Montréal. Tous les participants utilisaient un fauteuil roulant en raison de divers problèmes de mobilité. Nous avons effectué une entrevue individuelle semi-structurée avec chacun d'eux et analysé les transcriptions en utilisant une méthode thématique inductive.

Les entrevues révèlent que les personnes à mobilité réduite rencontrent de multiples barrières dans l'accès aux services dentaires. Celles-ci ont été classées en 11 difficultés rencontrées dans leur parcours de soins dentaires. Elles débutent avec le défi de trouver un dentiste accessible, d'être accepté par le dentiste, d'organiser le rendez-vous et le transport. Après avoir surmonté ces défis, les personnes utilisant un fauteuil roulant peuvent éprouver des difficultés supplémentaires pour entrer dans le bâtiment, se déplacer à l'intérieur de la clinique, et interagir avec le personnel. En outre, des difficultés se produisent

pendant les séances de traitement: être transféré dans le fauteuil dentaire peut être difficile ou parfois impossible; une fois dans le fauteuil dentaire, les gens peuvent éprouver des douleurs physiques, des spasmes musculaires ou d'autres sensations désagréables; le temps peut également être un problème car les sessions durent souvent plus longtemps que pour les autres personnes. Enfin, les obstacles financiers liés au coût des traitements dentaires s'avèrent des préoccupations récurrentes.

Globalement, notre étude montre que les personnes utilisant un fauteuil roulant sont victimes de discrimination dans l'accès aux services dentaires. Les défis que nous avons identifiés peuvent générer des inégalités de santé buccodentaire si les personnes avec un handicap physique renoncent aux services des professionnels dentaires. Nous croyons fermement qu'il est de la responsabilité de la société de supprimer les multiples obstacles auxquels font face les personnes utilisant un fauteuil roulant. Par conséquent, la présente étude propose une série de recommandations qui s'adressent à plusieurs secteurs de la société: le gouvernement, la profession dentaire, les facultés dentaires et les organisations qui représentent les personnes à mobilité réduite.

1. Introduction

Wheelchairs have enabled people with physical limitations to manage their daily lives with greater mobility. A great many people with various diseases, disabilities and past injuries use wheelchairs and this population grows every year (1, 2).

Despite the importance and rise of wheelchair use, the needs of people with disabilities have not been fully accommodated. As suggested by the social model of disability, the principal disabling factors of wheelchair use stem from the society that fails to take into account impairments and accessibility when creating physical and social environments (3). In order to live independently and fully participate in society, people using wheelchairs need accessible physical environments such as public buildings and transportation, accessible health care services and skilled staff with positive attitudes and awareness about disabilities (4). Unfortunately, these standards and services prove elusive to many. Moreover, the lack of access to health care services can follow from or compound other inequities, including lower access to education and employment (4-8) and a resulting rise in poverty and social exclusion (9, 10).

The existing literature consistently shows that accessing social and health services can be especially hard for people using a wheelchair (4). Generally people using a wheelchair have good health conditions (11); however, their disability or the use of adaptive devices may cause complications. These conditions may call for the use of more complex treatments and maintenance services (12, 13) to prevent the progress of an impairment or to prevent secondary health conditions (14, 15). Additionally, inappropriate structures in the health care system, the negative attitudes of health care workers and a lack of knowledge on the part of professionals regarding special needs of people with disabilities, can contribute to further barriers for this group. Consequently, people using a wheelchair are less satisfied with health care services (16-19) and have more secondary conditions that weaken their quality of life and participation in society (20, 21).

In the field of dentistry, several studies indeed show that people with disabilities have more untreated dental problems than the rest of the population (22, 23). Critically, oral health is the most neglected health need of people using a wheelchair on the part of both dental care and health care professionals and by people with disabilities as well. Studies show that health professionals do not consider the oral health of people with disabilities to be a high priority. Similarly, people with disabilities are typically more concerned with medical problems originating from their disability than those of oral health (24, 25).

Further research suggests that systemic diseases causing disabilities can have significant negative consequences on oral health and vice versa. For example, numerous medications prescribed for treating disabilities have negative side effects on the oral health of their users. For instance, immunosuppressive agent cyclosporine used in the treatment of severe rheumatoid arthritis causes gingival hyperplasia; besides, antispasmodics, anti parkinsonism and muscle relaxant medications cause xerostomia (26). In addition, health conditions and impairments of people with disabilities may affect their oral health. Cerebral palsy patients, for example, may experience severe bruxism, TMJ problems and tooth wear. Also, the consequences of these conditions can be grave as oral health has significant effects on the individual's general health, especially people with disabilities. Periodontal diseases, for instance, have shown an association with heart disease, stroke and diabetes (1, 27, 28).

While the literature on this subject shows that the inability to pay for dental services may provide a barrier to people with physical disabilities (1), little is known about their dental care pathways. In particular, the difficulties and challenges encountered in the process of accessing dental services have been ignored. Consequently, identifying these obstacles is an important step towards finding solutions to increase access to dental services and, ultimately, to improve the oral health and well-being of people with disabilities.

This research aims to approach this problem by seeking to better understand the difficulties faced by people using a wheelchair in accessing dental services. Moreover, it seeks to identify solutions that can facilitate the timely access to quality dental services on the part of this population.

2. Literature review

2.1. Disability definition

The concept of disability has transformed over time. While early models defined disability exclusively in medical terms, disability in more recent years has become recognized as a concept with a strong social dimension. Both concepts have been combined in the present classification system used in the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization (WHO). Statistics Canada adopted this model for its 2001 and 2006 Participation and Activity Limitations Surveys.

2.1.1. Medical or individual model of disability

As defined by the medical model, disability is a personal problem that results from health conditions such as trauma or disease (29, 30). Consequently, it follows that the solutions for such a problem are sought through individual adjustments and medical care provided by health professionals. At the policy level, accordingly, health care providers are exclusively tasked with improving the conditions of people with disabilities.

The medical model has long been the traditional way of describing disability, although it has increasingly become the subject of criticism. A noted weakness of this model is the absence of the social factors within its calculus of disabling factors. Additionally, the medical model inherently defines behaviour on a spectrum of “normal” and “abnormal” activities such as walking and using a wheelchair, respectively. This approach, which carries the stigma of negative social judgemental, can be further damaging to individuals with disabilities. Seeing disability as a medical issue thus outlines the scope and limitations of the medical model (29).

2.1.2. Social model of disability

A different model of disability emerged from the disability movement's efforts to use the language of civil rights to express the economic, social and environmental barriers of disability (29). As sociologist and advocate Saad Nagi noted in his pivotal article of 1965, "every day, people with disabilities encounter barriers to their daily activities that are not caused by their impairments, but by an environment that does not take account of their impairment."(3) The social model of disability (29) resulted from the increasing articulation of disability in terms of the behaviour of others and of environmental barriers preventing people with disability from fully participating in society (29).

In this framework, disability is not seen as the characteristic of an individual, but rather the result of several conditions including the many social and physical barriers produced by society. Thus, society is recognized as the main element responsible for disability and it becomes incumbent upon it to change its social and physical environment so that people with disabilities may more fully participate in social life. For example, a person with spinal cord injury who cannot walk will also be unable to use public transport in most communities, if she or he is not provided with elevators in metro stations. This lack of capacity, rather than residing in the body of the person with disabilities, is instead seen as a failure of her or his society.

The social model implicates the inaccessible environment (instead of the individuals themselves) as responsible for the limited participation of people with disabilities in society. As a result, this model aims to ameliorate the economic, social and physical obstacles of disability by decreasing discrimination and increasing community accessibility through, for example, building design, transportation and employment opportunities (29, 31, 32). From this point of view, disability is a question of human rights, and a lack of access is seen as an infringement of these rights.

The two following questions clearly illustrates the difference between the medical and social models (29, 33). Whereas the medical model asks: “can you tell me what is wrong with you?” the social model asks: “can you tell me what is wrong with society?”(33).

2.1.3. WHO classification of disability (ICF)

In response to the challenges to the medical model of disability, WHO created ICF: a new framework to measure health and disability at individual and population levels (34, 35). Whereas the previous standards of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) had not considered the role of environmental factors in creating disability, the new classification system combines the medical and social models into a “bio-psycho-social model” (4, 36). Neither a measurement tool nor survey instrument, the ICF is a standard classification that can help in estimating disability prevalence for health and disability statistics (4).

The importance and influence of this standard has been wide-reaching. Statistics Canada, for example, employed this classification in 2001 and 2006 in its “Participation and Activity Limitations Surveys” (30, 34, 37). A large number of studies have also used the ICF model to define disability (38).

As part of its overall definition of **Disability**, ICF presents a description for **Functioning**, categorizing its related problems in three areas:

1. Impairments refer to problems in body function or changes in body structure, for instance, blindness or paralysis.
2. Activity limitations refer to problems to carry out daily activities, for example, walking.
3. Participation restrictions refer to difficulties in participating in different areas of social life, for example, lack of equal opportunities of employment or problems when using transportation (4).

ICF further differentiates between **Health Conditions:** diseases, injuries and disorders in body; and **Impairments:** symptoms of health conditions which appear as decreased body functions and structures.

According to the ICF, functioning and disability are the result of an interaction between health conditions and contextual factors (personal and environmental). Disability is a term that covers impairments, activity limitations and participation restrictions which are experienced by people with disabilities (34, 37, 39). Disability is the product of a problem occurring in one or all three areas of functioning and in the interaction of health conditions with **Environmental** and **Personal Factors**.

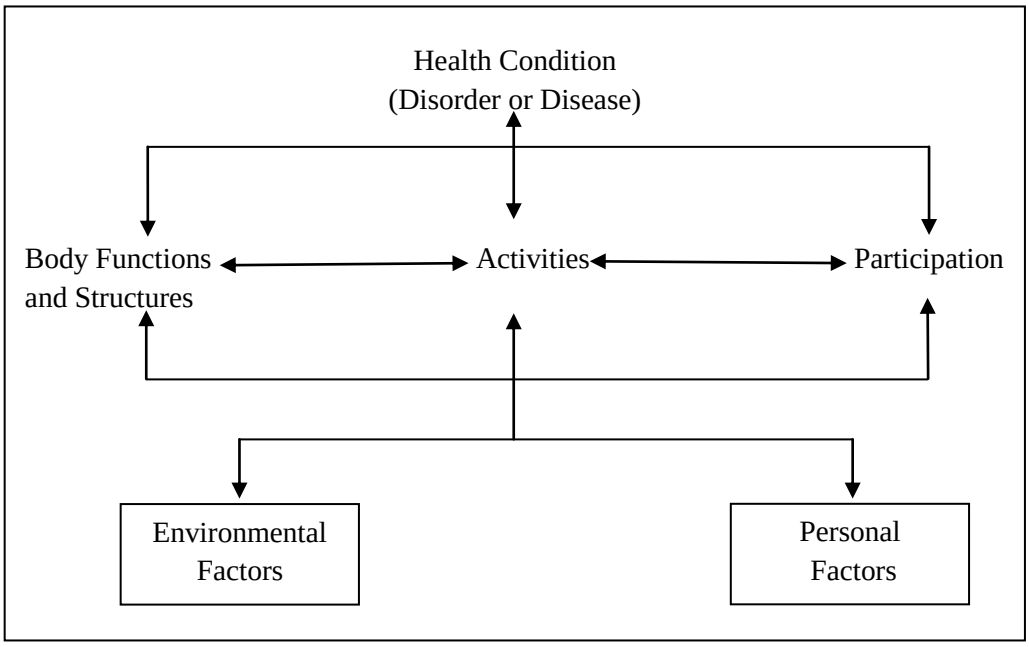
Environmental factors include all barriers and facilitators of the world in which people with different levels of functioning must live and act. This encompasses products and technology; the natural and built environment; support and relationships; social attitudes; and services, systems, and policies.

Personal factors are factors such as motivation and self-esteem that affect individuals and create differences between her or his capacities and actual performance. This difference could help to highlight the effects of the environment on performance and suggest grounds for change (4).

ICF presents this model as a diagram that can be used as a starting point in the study of the many processes involved in functioning and disability.

As this figure suggests, disability is not a personal characteristic. Rather, as the United Nations Convention on the Rights of persons with Disabilities states: “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others”.

Figure 1. Diagram of interactions between the components of ICF



Source: World Health Organization, 2001.

2.2. Population

2.2.1. Worldwide

Disability is a worldwide phenomenon experienced differently from nation to nation. The prevalence of disability has been ambitiously examined by two major surveys using the ICF framework: the WHO World Health Survey of 2002–2004, by far the largest multinational health and disability survey ever conducted; and the WHO Global Burden of Disease study, a 2004 update (the first Global Burden of Disease study was done by the World Bank in 1990) (4, 40). These two surveys estimate that in 2010 there will be about 15.6% to 19.4% (758 to 975 million) persons age 15 and over living with disabilities. Among them, 110-190 million (2.2% to 3.8% of the world population) will experience significant difficulties in functioning (34, 41, 42).

2.2.2. Canada

In 2001 and 2006, Statistics Canada conducted its own survey on the national prevalence of disabilities called "National Participation and Activity Limitation Survey" (PALS) that adopted ICF's concept of functional disability. As Table 1 illustrates, these surveys show a marked increase in the number of Canadians who reported having a disability. In 2006 this number had increased to 4.4 million of Canada's 30.9 million total population 15 years of age or older (14.3%). Among this population, about 2.9 million adults (11.5%) had a disability related to mobility.

The 2006 PALS also revealed that, among Canadians aged 15 and over, 1.7 million people (6.6%) had a severe or very severe disability. Moderate disability was reported by 4.1% of individuals (1,045,500 people), while 5.9% of this sample indicated a mild disability (1,492,580 people). The patterns of severity in disability were relatively unchanged for adults between 2001 and 2006.

Table 1. Number and population of disability in adults of 15 years of age or older in 2006 (30)

Total Canadians with disabilities	Disability related to mobility	Severe or very sever disability	Moderate disability	Mild disability
4.4 million (14.3%)	2.9 million (11.5%)	1.7 million (6.6%)	1 million (4.1%)	1.5 million (5.9%)

2.2.3. Quebec

In 2006, 768,140 persons (10.4%) out of 7.4 million people 15 years or older reported having a disability in the province of Quebec. In the same population, 8.5% (526,450 persons; 6.8 % men, 10.2 % women) had a disability related to

mobility, which proved to be the most common type of disability (15-64 years: 5.3%; 65 years and older: 25.6 %) (43).

2.2.4. Wheelchair users worldwide and in Canada

At the end of the 20th century, the number of people using wheelchairs and scooters increased significantly. According to the National Health Interview Survey (NHIS), from 1957 to 1995 this population grew 4 fold in the United States, increasing from 409,000 to 1,700,000 individuals (2).

In Canada, during the years 2000-2001, about 0.6% (155,000) of the household population aged 12 and over living in private households needed a wheelchair. Moreover, the rate of wheelchair use increased with age: 0.3 % of the household population aged between 12 and 44 used a wheelchair, while at the age of 85 or over this rate reached 7%. A similar trend can be observed in the use of other mobility devices. Additionally, people with lower to middle incomes were more likely to use mobility support devices than those with middle-high and high incomes (2, 44, 45).

2.3. Assistive devices

There is yet no comprehensive information available on the rate of wheeled mobility device use. Studies show that the number of people using a wheelchair increases by 5.9% every year; this population is 6 times larger than it was 30 years ago. A growing demographic of older people and technological developments have played a significant role in this increase (2).

Worldwide, many people with disabilities, especially people with mobility impairments, lack access to medical equipment such as assistive equipment or health care providers such as rehabilitative services (4, 20). For example, a large number of people with multiple sclerosis, spinal cord injuries, and cerebral palsy

still do not have timely access to assistive devices like wheelchairs and rehabilitation services (46).

These challenges are also present in Canada. The first cycle of the Canadian Community Health Survey conducted by Statistics Canada in 2000-2001 shows that about 0.6% of Canadians aged 12 or over (about 155,000 people) need a wheelchair to assist them in basic mobility. An additional 2.1% (about 540,000 people) require other assistive devices such as crutches, canes or braces (44).

While approximately 60% of people using a wheelchair are unable to walk without assistance (2), no tool exists to measure and differentiate between different kinds of mobility related impairments. Some people cannot walk because of a lack of balance, while others struggle with a lack of strength and endurance. Some wheelchair users can control their legs sufficiently to walk a few steps while others are unable to do so.

The rate of wheelchair use corresponds with the level of difficulty in walking. In the U.S., wheelchairs are used by 10% of people with some difficulty walking, 23% of people with a lot of difficulty walking, and 58% of people who are otherwise unable to walk (2).

Although almost all people using a mobility device have a mobility limitation, not all people with a mobility limitation use or have access to assistive devices (2). Some people with mobility related disabilities do not use a wheelchair because they have human assistance. In the future, however, as people have fewer children, it is expected that more people will be dependent on assistive devices for basic mobility (47). Importantly, delay or lack of access to this equipment may cause negative and more costly health conditions (48).

Many conditions play an important role in choosing an assistive device, be it a cane, crutch, scooter or wheelchair. These factors may include the severity of the mobility impairment, cost, and the resulting levels of accessibility in the environment to users of a particular device. Some people who would otherwise

benefit from a wheelchair still choose a less optimal device (e.g., canes and crutches) because the characteristics of the built environments of their homes and communities cannot accommodate a wheelchair without costly modifications (2).

The use of electric powered wheelchairs is increasing as more and more wheelchair users switch from a manual to an electric wheelchair. This trend is especially noticeable in persons with progressive conditions or high levels of impairment (49, 50).

Consequently, in order to be able to live independently and maintain their functional ability, most people with disabilities require durable medical equipment or assistive devices. However, existing health plans do not provide such equipment to all those who need them. For example, in the U.S. 50% of assistive equipment is individually purchased by people with disabilities without the help of a third party (51).

2.4. Definition of access

While previously ignored (45), the concept of access has become the subject of many studies and the focus of new approaches towards disability. This concept incorporates environmental factors and their important role in the quality of life of people with disabilities. The relation between these factors and individuals with disabilities evinces the level of participation of disabled persons in society (52, 53).

The United Nations (UN) emphasizes the need for accessibility for people with disabilities. Rule 5 of the standard rules of the UN declares:

> *States should recognise the overall importance of accessibility in the process of the equalisation of opportunities in all spheres of society. For persons with disabilities of any kind, states should (a) introduce programmes of action to make the physical environment accessible; and*

(b) undertake measures to provide access to information and communication (53).

Accessibility is composed of three aspects: access to the physical environment, access to information, and access to social services and activities. In the history of disability issues, physical accessibility has long been the most predominant subject of discussion. More recently, however, greater attention has been paid to the other aspects of access (54).

2.4.1. Universal design

There are two main approaches to the issue of accessibility: **Traditional Design** and **Universal Design**. Traditional or "accessible" design relies upon the designation of individuals into two groups: the normal population and the abnormal population, which includes people with disabilities. A study of the unique needs of the abnormal population will then enable a designer to create or adapt an existing, inaccessible product or building to make it more accessible.

Universal design, conversely, avoids this reactive, judgemental approach by considering users as a singular population with a variety of characteristics and abilities. Resultantly, design decisions are made such that products and buildings can be useful to a maximum number of people in the population from their very inception. In the words of universal design pioneer Sandra Iwarsson: "universal design is about social inclusion while accessibility measures are implemented after the basic design of a building or a product represents exclusion," (54).

As the concept of universal design develops, more and more new definitions are being created. Innovative frameworks emerge from this concept to consider a diversity of end-users, their preferences, environmental characteristics, and limiting situations for individuals with and without disabilities. Regardless of the application, however, the end goal is still the development of more flexible and adaptable solutions for a wider range of users (55, 56).

In the ICF, WHO defines the essential environmental components that need to be accessible to people with disabilities to enable them to act and live in society like other members of the population. These components include: accessible public buildings and transportation; assistive equipment; rehabilitation and health care services; skilled staff who provide services to people with disabilities; adequate financial resources; the involvement of people with disabilities in issues that are directly related to their own lives; inclusive education; positive attitudes and awareness about people with disabilities; and standard physical environments and policies to support these requirements. These essential components are connected and, if some should prove inaccessible, people with disabilities will not be able to completely benefit from other facilities. It is noteworthy that accessible environments not only benefit people with disabilities but also other groups of individuals. Ramps, for example, are also useful for parents with strollers (4).

Inaccessible environments have profoundly negative consequences on the lives of people with disabilities. These individuals are less active in social activities and are more dependent on others for living without the necessary conditions for accessibility. For instance, as we will explain later, the rate of poverty among the disabled population is higher than average and these persons generally experience poorer health conditions and lower educational outcomes. They are less economically active and are less likely to live independently (4).

2.4.2. Health Care

According to Penchansky, access in the field of health care can be defined as "the degree of 'fit' between the clients and the system" (57). Penchansky further defines access in health care in terms of the following five dimensions: availability, accessibility, accommodation, affordability and acceptability. Here, the terms "access" and "accessibility" have different meanings. "Access" is a comprehensive term that describes numerous characteristics of the health care system, from the capacity to accept patients, appointment hours and costs to

attitudes and perceptions of health professionals. “Accessibility” has a more specific meaning and refers to the location of the services and the physical characteristics of health care locations. As such, accessibility can be understood as a subset of access.

Health care workers sometimes have inaccurate perceptions of the accessibility of their clinics. In a study looking into the physical accessibility of health care clinics, all participating clinic managers claimed that their clinics were wheelchair accessible, even though many of these clinics did not meet the requirements of the American Disabilities Act (ADA) guidelines regarding accessibility. Although patients with a wheelchair were able to “enter” the building, examination room and washroom, some clinics did not have adjustable examination tables, adapted washrooms or skilled workers to assist with difficult physical transfers (58). Access in healthcare, therefore, remains an ongoing challenge.

2.5. Education and employment of people with disabilities

2.5.1. Education

The results of the World Health Survey show that people with disabilities have significantly lower rates of primary school completion and fewer mean years of education than other demographics. The rate of children with disabilities who do not start school or leave school prematurely is higher than that of other children. Throughout history, a large number of children and adults with disabilities have been excluded from the regular education system, largely being relegated to separate, specialty schools. However problematic such exclusions may be, even these schools were not universally available and did not provide education for children with certain types of disabilities. Education for children with disabilities has particular importance because it is a valuable tool to help them participate in employment and other social activities (4).

2.5.2. Employment

The employment rate of people with disabilities in both developed and developing countries is lower than that of people without disabilities (5-8). A large body of evidence confirms the poor socio-economic status of people with disabilities, reflecting their employment conditions (4). As this population typically works less frequently and for less hours, their level of income resultantly suffers. In Canada, in a six-year period, the average person with a disability will work 1.6 years less than others and will earn almost 20% less than average (59, 60). Moreover, women with disabilities are particularly ill-advantaged, earning even less than men with disabilities (61).

These educational, economic and social factors are compounded by negative attitudes about the capabilities of people with disabilities on the part of some employers and a concomitant reluctance to have a person with a disability in their workplace, thus further restricting the participation of people with disabilities in the labour market (5, 62).

One of the most significant consequences of the under and unemployment of people with disabilities is poverty (63, 64). As this population is more likely to be unemployed, they are also more likely to live in poverty and face social exclusion. These obstacles have additional negative effects on people with disabilities' well-being (9, 10).

Studies show that Subjective Well-Being or SWB -referring to the level of life satisfaction or happiness- is lower in people with disabilities than in people without disabilities (65-70). SWB changes according to the severity of disability but it is not associated with type of disability. As previously mentioned, unemployment and poverty are factors that decrease SWB (59). An Australian study shows that the adversity and reduced access to resources that follow from disabilities have more negative effects on the psychological well-being of people with disabilities than the presence of the impairment and health conditions themselves (71).

2.6. Health care for people with disabilities

2.6.1. Health conditions of people with disabilities

Compared to people without a disability, people with disabilities face more barriers and are less satisfied with health care services (16-19). Although they are generally otherwise in good health conditions, they may be more susceptible to certain health problems because of their disability (12). For example, in the U.S. in 1996, this population was the largest group of health care users, composing over 60% of overnight hospital stays, over 40% of all prescriptions and refills, and over a third of physician visits. However, despite the prevalence of this group's use of health care resources, health care providers are not well-equipped to provide quality care for this population and people with disabilities report significant barriers in access to health care services (12).

It is unfortunately the case that the higher the severity of the disability and the poorer the health condition, the lower a person's access will be to health care (17, 21, 72). Additionally, the costs of health services used and the satisfaction level of the patient with disability also depend on their health conditions and the severity of their disability (73). In Québec in 2006, 59% of people aged 15 or over with a disability believed that their health was fair or poor, while only 32% of people without disabilities held the same view (43). In addition, 23% of this population with a disability was not reimbursed in a period of 12 months by a private insurance company or the government for the costs they incurred for health care and social services (43).

Furthermore, people with disabilities who had impairments at a young age are at a higher risk of chronic health conditions. For example, people who have a mobility limitation may have coronary heart disease earlier than someone without that impairment (74). Some of the health conditions of people with disabilities that contribute to this heightened vulnerability include:

- The possible need for longer and more complex treatment for a health problem.
- The possible need for personal support, permanent medical supervision and medical equipment.
- A possibly longer recovery time due to limitations in access to therapies after an acute illness or injury (12).

In general, this group has a need for more post-acute and maintaining services than the rest of the population. As health care needs of people with disabilities are often more progressive and complex, special types of health care are increasingly required.

Importantly, the consequences of receiving poor health care and lack of access to timely quality health care in this group are very serious. Because they have a "thinner margin of health," these barriers lead to grave physical, social, emotional, and economic consequences (14, 15, 75). These factors also increase the importance of preventive health measures in this population (11, 76). However, the access and use of primary preventive health services for people with disabilities is less than that of people without disabilities (77, 78).

Ultimately, lack of adequate health care may cause secondary conditions and health deteriorations which may worsen these individual's quality of life, making them unable to participate effectively and independently in community activities. These secondary conditions may also lead to unaffordable health care costs (20, 21).

2.6.2. Structure of the health care system

An inappropriate structure of the health care and referral system affects the quality of services that most of the general physicians provide for people with disabilities (79). For example, in the U.S. about 4.5 million adults with disabilities are not

covered by any kind of health insurance. Half the people in this group work but still cannot afford private or even public health insurance (80).

In addition, health services are not distributed fairly and health care systems do not provide efficient resources for people with disabilities (81). For example, in the U.S., the health care system concentrates on acute health care needs while 75% of all medical spending is for chronic conditions. As people with disabilities have more chronic conditions, the American health care system is ill-suited to their needs (82). Finally, people with disabilities may sometimes need an additional consultation time because of their complex health care needs. However, health care providers are often not reimbursed for this additional cost. Thereby creating a possible barrier for health care practitioners to provide due service (83-85).

A single inflexible health plan cannot provide quality care to people with disabilities because, in addition to the specific health conditions which originate from a specific impairment, other related or additional health conditions may occur outside the scope of an individual's initial coverage. Some of these associated health problems are similar to those of elderly people, children, people with chronic illnesses and people with low incomes. Consequently, there is a need for health plans which consider the intersection of personal characteristics, environmental factors, and health care (86, 87).

2.6.3. Attitudes of health care workers

The respect, knowledge and support of health care providers in relation to people with disabilities can have a great impact on the quality of health care for this group. Some people with disabilities report that they are unwilling to seek health care because of past experiences of stigmatization and discrimination (88). Furthermore, leaders of disability right movements hold that the health care system marginalizes people with disabilities by following the medical model of

disability whereby people with disabilities are made to assume a role of sick person (89).

Negative attitudes and misconceptions act as significant obstacles to provide quality service to people with disabilities. Worryingly, health care professionals' uncomfortable feelings when treating people with disabilities can have negative influences on the process of treatment and clinical decision making, leading to harmful effects on a patient with a disability (83, 90, 91). These experiences can cause a distrust of health providers on the part of people with disabilities. Therefore, to avoid insensitivity and disrespect, many individuals may choose to rely on self-diagnosis and self-treatment (13, 92).

2.6.4. Knowledge of health care professionals about people with disabilities

Most health care workers have neither the fundamental knowledge nor adequate experience to manage the health care needs of people with disabilities (13, 84, 93). Distinguishing between the different health problems of people with disabilities and understanding whether there is a relation between a particular problem and a pre-existing disability is a difficult task at which all health professionals do not succeed (94). Additionally, in some cases the complex conditions of people with disabilities call for specific treatments that a health care provider, who is not updated on new research and guidelines, may fail to provide for the patient. This skill gap, moreover, sometimes results in risky experiences and insufficient examinations (95).

2.6.5. Training

This problem may be further ameliorated by recognizing the important role of continuing education with regard to people with disabilities (96). Health care workers including general practitioners do not receive adequate training at the undergraduate level to manage the health care needs of people with disabilities

(96-98) or communicate efficiently with them (84). Studies show that training undergraduate medical students on communication skills, even for a couple of hours, has a significant effect on their attitudes towards people with disabilities (99). According to Sanchez et al. the health care community should be trained and assessed regularly to maintain accessible health care services for people with disabilities and to remove important obstacles that prevent these persons from receiving appropriate health care. Managers and supervisors should also be made aware of the special needs of people with disabilities (58).

On the other hand, people with disabilities can also benefit from training on how to better research the accessibility of a clinic when making an appointment. Oftentimes, simple inquiries about "wheelchair accessibility are insufficient to ascertain the real conditions of a clinic because staff perceptions can differ wildly and may not accord with standard physical accessibility guidelines" (58).

2.6.6. Conclusion

In conclusion, some of the barriers to quality health care services for people with disabilities are poor physical access; transportation problems; inadequate knowledge of health care workers, especially physicians and specialists regarding specific health conditions of people with disabilities; insufficient health insurance or changes in insurance with its concomitant negative effects on continuity of care; lack of access to service information; and problems in identifying the right general and specialist physicians (81, 100-102).

Despite the deficiencies of health services, only one third of people who face a problem submit their complaints about quality of services formally or informally. The rest remain silent. This observation is pertinent for both people with disabilities and without. Of those complaints that are made, most are verbal and are at the local level. Of those that are more formally submitted, most complaints are not registered or sent to management for review (103, 104).

Studying these problems meet further challenges; despite the wide range of difficulties that people with disabilities face in receiving appropriate health care and the need for comprehensive studies to detect these barriers, most surveys and qualitative studies undertaken to date focus on one or a select few disabilities or diagnoses in a specific group of people in a specific area of health care. Drainoni believes that to study barriers in accessing health care services, the limited function which is a result of a disease is more relevant than the disease itself; for example several kinds of diseases or trauma could result in using a wheelchair or not being able to see, hear or speak (13). Accordingly, it is more efficient to examine the relationship between health care environment and patient's functional limitations, rather than specific diseases. However, there are few studies looking into the access of people with disabilities comprehensively (13), and even fewer qualitative studies that investigate the consequences of insufficient and inaccessible health care services from the point of view of people with disabilities themselves (105-107).

2.7. Oral health of people with disabilities

2.7.1. Incidence of dental diseases among people with disabilities

Dental caries are the most prevalent disease in people with intellectual and developmental disabilities worldwide, leading researchers to conclude that "dental treatment is the greatest unattended health need of the disabled," (24). People with disabilities have more untreated caries and missing teeth, poorer oral hygiene, and a greater number of traumatic dental injuries and dental diseases than the rest of the population (22, 23). These rates of dental problems are even greater for people with disabilities living in rural areas (23). Additionally, within the wider population of individuals with disabilities, less attention is given to adults in providing dental care. While children and the elderly with disabilities have traditionally received priority in their dental care, the needs of adults are more likely to be ignored (1).

On the other hand, general health conditions of people with disabilities affect their oral health. An individual's medical problems, the side effects of medications, and impairment itself can all accentuate the oral health problems of a person with a disability (108). Dental diseases have more negative effects on the general health and function of people with disabilities compared to people without disabilities. Also, people with disabilities, compared to those without disabilities, are more likely identify dental problems as a negative influence on their ability to find employment (109, 110).

2.7.2. Priority of oral health care for people with disabilities and dental care professionals

A study conducted in Sweden in 2007 shows that compared to other health issues, people with disabilities may not give high priority to dental and oral health care. Visits to dental clinics on the part of this population tend to be at the request of dental professionals rather than for the receipt of preventative or routine care. Therefore, it is the responsibility of dental professionals to equally promote the oral health of people with disabilities as with the rest of the population (25).

Recently, awareness of the need to provide quality medical services for people with disabilities has increased. However, dental services are still given a lower priority than other types of care (111). As shown by a Swedish qualitative study interviewing 17 medical care professionals (doctors, nurses, speech-language pathologists, hospital teachers and physiotherapists), oral health issues are not included in the treatment plan of children with disabilities. This omission follows from three principal reasons: organizational and structural challenges, financial problems, and insufficient knowledge on the part of medical personnel about oral and orofacial health (112).

2.7.3. Preventive care

In addition to the inadequate attention given to the dental care of this population, an attentiveness to the prevention of dental diseases is particularly lacking (22, 23). According to a survey conducted among Irish dentists the most common services given to people with special needs in dental clinics are dental emergency procedures, whereas preventive care is neglected (113). Besides, most patients with disabilities and their caregivers may not be aware of existing preventive programs and techniques. It is considered the responsibility of dental professionals to inform this population and provide these programs in dental clinics (114).

The level of cooperation of people with intellectual and developmental disabilities with dental treatments differ from person to person. Physical and cognitive limitations may affect oral health maintenance. For example, an individual with an intellectual disability may bite down on the tooth brush, refuse to open their mouth or only open it slightly. Caregivers, moreover, may not possess the skills required to perform preventive oral health care on behalf of people with disabilities or may not even be aware of their oral care needs (115).

2.7.4. Financial barriers

In addition to sensory and assistive barriers, people with disabilities are less likely to use dental services because of their socio-economical disadvantage. For example, in the U.S. as well as in Canada the costs of dental services are generally paid from private resources or employment-based insurance. Unfortunately, people with disabilities (especially those with a severe disability) are more likely to be unemployed or employed part-time without dental insurance and with a low income. Consequently, paying for dental costs is a greater challenge for this group. Moreover, as people with severe disabilities incur several additional

expenses because of their disability, dental care may take on an even lower priority (1).

2.7.5. Effect of dental professionals' knowledge, education and attitudes in treating people with disabilities

Some of the problems faced by people with disabilities surround issues of access to dental services and denial of services. Several studies show that dentists may refuse care to people with disabilities due to a lack of education and clinical skills (1, 113, 116). Additionally, existing prejudices may cause dental professionals to think that oral health is a low priority for this group (116).

Several studies indeed show that dental students may lack adequate special needs training including didactic, clinical and hands-on learning experiences (117, 118). A study conducted in the U.S. found that only 53% of dentists had received some form of special needs training. This training typically consisted of less than 5 hours of classes and even fewer hours of clinical training and exposure to patients with special needs in American and Canadian dental schools (119). This lack of training may have important implications, as dentists without theoretical and practical trainings are less likely to accept treating people with special needs (120).

On the other hand, sometimes dentists undertake tasks that they are not trained for. In 2009, in a survey of dentists in the U.S., 76% stated that they had rarely treated patients with spinal cord injury while they sat in their own wheelchairs. Rather, they had transferred these patients to a dental chair. However, only 28% had been trained in transferring techniques and only 20% had the knowledge of how to use proper body mechanics for the safe transferring of wheelchair bound people. It shows that more than 70% of the respondents reported unsafe transferring techniques (117). Further research has shown that in the U.S. 90% of dental professionals were not familiar with the serious condition of autonomic

dysreflexia in spinal cord injury patients and were not trained to manage any manifestations of this condition during dental procedures (117).

Finally, the negative attitudes of professionals play an important role in their willingness to treat people with disabilities. Training dental professionals and dental students can increase positive attitudes on the part of professionals and their willingness to treat people with disabilities. Unfortunately, this training has a low priority in dental schools (1, 117, 121, 122).

2.8. Summary of the literature review

People with disabilities, have more untreated oral health problem especially because of trauma and their general health conditions. However, they do not use dental services as much as the rest of the population. Despite increasing awareness of health professionals regarding the importance of quality medical services for people with disabilities, oral health care is not given similar priority by both the people with disabilities and health care professionals. Lack of motivation among people with disabilities to receive dental services may be a result of higher number of difficulties that this group face in their dental care pathway. On the other hand, lack of knowledge and skills about special needs of people with disabilities could create reluctance among dental professionals to treat this group of patients.

Although a large number of studies have been conducted to investigate oral health care of persons with special health care needs, there are only a few qualitative and quantitative studies investigating problems of people using a wheelchair regarding dental services. In addition, the majority of the studies use quantitative methodology. Consequently, we still lack a good understanding of people using wheelchairs' perspectives on access to dental services. In this project, we aim to better understand how people using a wheelchair experience access to dental services as this subject has not been enough investigated. We use a qualitative

approach as it is an ideal way to understand people with disabilities' experiences from their viewpoint. Qualitative interviews have the potential to discover surprising results and original findings regarding people with disabilities' personal experiences and their own definition of disability (123).

3. Aims and objectives

3.1. Aims

The aim of this research is to better understand the perspectives of people with physical disabilities with respect to dental services. In particular, we would like to deepen our knowledge of how dental services are used and experienced by people who use a wheelchair and to identify the challenges that they face. Ultimately, we would like to contribute to the reduction of existing inequalities and improve the oral health of people with physical disabilities.

3.2. Objectives

We will pursue the following two objectives:

- To better understand the difficulties that people using a wheelchair may face in accessing dental services.
- To identify solutions that facilitate their timely access to quality dental services.

4. Methodology

4.1. Participatory approach

We adopted a participatory approach and a qualitative descriptive research design. Participatory research is broadly defined as, "systematic inquiry, with the collaboration of those affected by the issue being studied for purposes of education and taking action or effecting change" (124). Participatory research thereby seeks to empower its participants by enabling this group to play a major role in addressing and solving an issue that they identify as important to them. We chose a participatory approach because it provided us the opportunity to collaborate with people with physical disabilities who were directly affected by the issue of access.

4.1.1. Development of the advisory committee

This project is based on a partnership linking three different groups of constituents: people with physical disabilities, dental professionals, and dental educators. The three groups collaborated with the project through an advisory committee that provided advice during all stages: from the definition of the research question at the beginning to the data interpretation and planned knowledge translation at the end.

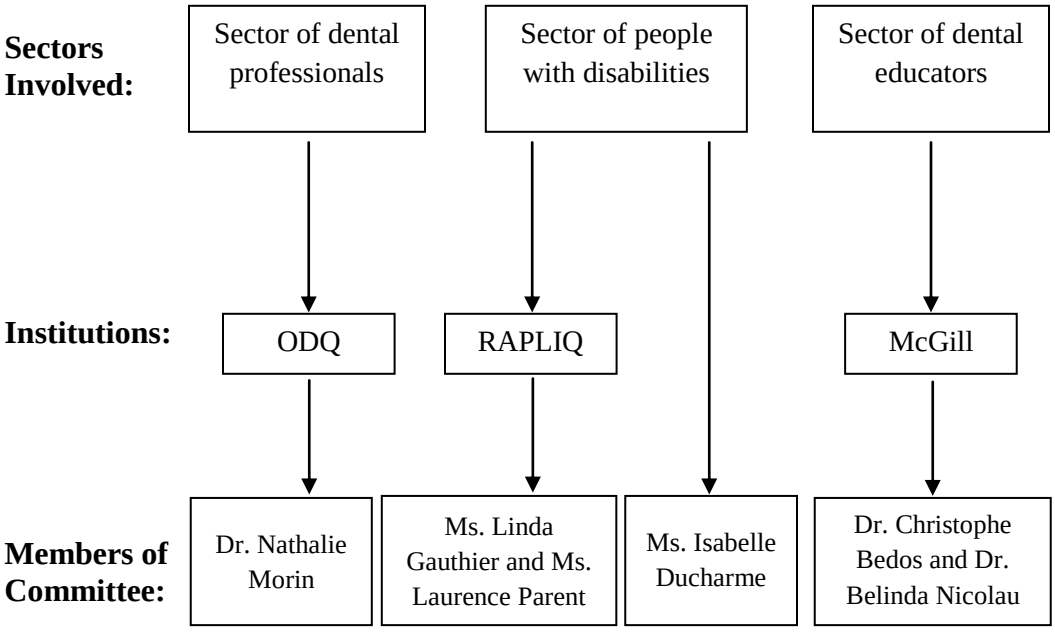
A long process of community networking and research was required in order to build this committee. To begin with, we made a list of organizations representing people with disabilities in Montreal, located by internet search and consultation with my supervisors. We also benefited from additional advice from other members of the Oral Health and Society Division of McGill's Faculty of Dentistry especially Ms. Marie-Claude Loignon and Dr. Frances Power who had previous experience in collaborating with various organizations. We then contacted several organizations such as Kéroul, Alter Go, Viomax and

Mouvement PHAS via phone and email to provide them with a short preliminary description of my project. Subsequent visits to advocacy groups such as RAPLIQ (Regroupement des activistes pour l'inclusion au Quebec), day centers like Action Center, and the OSD (McGill's Office of Students with Disabilities) provided further points of contact and allowed me to discuss my project with their presidents and directors. Action Center and OSD agreed to assist in the recruitment of participants for interviews. Moreover, Ms. Linda Gauthier, the president and Ms. Laurence Parent the vice-president of RAPLIQ, and Ms. Isabelle Ducharme, from Kéroul, agreed to take on roles within the advisory committee and further assist with recruitment.

Similarly, my supervisor introduced me to Dr. Nathalie Morin, a member of the Order of Dentists of Quebec as well as the Director of Professional Services and the Secretary of the Inspection Committee. Following correspondence and a productive meeting, she also agreed to join the project's advisory committee.

This process began in September of 2011; it took about four months to recruit and assemble the potential members of the advisory committee. Figure 2 summarizes the sectors and institutions represented by the committee.

Figure 2. Sectors and institutions represented by members of the advisory committee



4.1.2. Role of the advisory committee

The members collaborated individually and through committee meetings at different stages of the project. Initial, individual meetings were followed by a group meeting on the 30th of May, 2012. Further meetings may occur even after the conclusion of this thesis.

Over the course of several meetings, the individual committee members contributed to and collaborated in defining the scope of the research. The purpose of these initial, individual meetings was to discuss and refine the research question. Subsequently, two meetings were conducted with another member, a wheelchair user, to help refine the interview guide. Based on the ensuing discussions, additional questions were added to further address issues faced by the wheelchair-using population. As mentioned previously, two members of the

committee, who are wheelchair users and actively participate in disability related organizations, also helped in the recruitment of participants.

Later, in the group meeting, the advisory committee provided further contributions. The results of the first 10 interviews, possible avenues of knowledge translation, and the feasibility of implementing these activities were discussed. One suggestion, for example, concerned the role of the Order of Dentists of Quebec in educating dentists about the needs of people with physical disabilities, while another explored the possibility of devising a questionnaire to be completed by dentists to assess the level of accessibility of their dental offices.

4.2. Qualitative design

When designing the study, we chose a qualitative descriptive design: an approach that is particularly appropriate to explore phenomena about which very little is known (125). As explained by Patton: "qualitative data describe. [These data sets] take us as readers, into the time and place of the observation so that we know what it was like to have been there. They capture and communicate someone else's experience of the world in his or her own words..." Specifically, qualitative descriptive design "offers a comprehensive summary of an event in the everyday terms of those events" (126). Accordingly, we sought to capitalize on these strengths in our attempt to explore, understand and represent the points of view of people with disabilities with respect to access to dental services.

4.3. Data collection

Among the various techniques of qualitative data gathering, qualitative interviews best suited the purposes of the project. Using this method, a researcher engages individuals with relevant experience or knowledge in conversation. Subsequently, the researcher "reconstructs" external events by using these multiple reports to

construct an overall picture of the problem (127). Qualitative interviews can be classified into four basic categories: focus groups, internet interviews, casual conversations, and semi-structured and unstructured interviews (127). For the purposes of this study, individual semi-structured interviews were conducted.

In qualitative interviewing, rather than finding answers for fixed yes-no or agree-disagree questions, the participant is not limited to specific categorical answers. Instead, because the researcher is interested in experiences and examples, she or he asks open-ended questions posed neither with a predetermined answer in mind nor in a rigid order. The participant is thereby encouraged to provide answers however she or he would like and is further at liberty to raise new issues or even disagree with the questions themselves (127). In this study, we prepared a limited number of questions in the form of an interview guide concerning potentially important issues faced by people with disabilities regarding dental services. I -as interviewer- also prepared myself to ask follow-up questions and to use probes in conversation. The process of these interviews is further described in the following sections.

4.3.1. Sampling

This study employs a purposeful sampling strategy because, as Patton says, "the logic and power of purposeful sampling derive from the emphasis on in-depth understanding," (128). Purposeful sampling is also called judgment sampling because the researcher evaluates and selects an informant or community that complements the researcher's purpose. This strategy aims to select "information-rich" cases so that the researcher will be able to focus resources in order to examine the issues related to the research question (128).

More specifically, we selected a "criterion sampling" strategy. As described by Patton, "the logic of criterion sampling is to review and study all cases that meet some predetermined criterion of importance." In this project the main criterion for

choosing participants was the full-time use of a wheelchair as we were interested in limitations which originate from this form of limited mobility. Although the causes of disability and socio-economic backgrounds varied among the participants, the use of a wheelchair was a shared characteristic among all the participants. Their other demographic traits are summarised in Table 3 in the Results section.

The three inclusion criteria for the participants were: (i) living with physical disabilities requiring use of a wheelchair; (ii) being between 18 and 65 years of age; (iii) being able to speak English; (iv) having looked for dental services, consulted a dentist or having experienced an oral health problem during the last 2 years.

Since our objective was to explore the barriers faced by people using a wheelchair when seeking dental services, we narrowed our search to people who use a wheelchair in their everyday life. We focused on adults using a wheelchair because their oral health conditions and needs are poorly studied. The participants were also selected based on their ability to speak English as it was the language in which I as interviewer was most comfortable working with. As we expected the participants to describe their own experiences regarding dental services, we further selected participants based on their relevant experience within the last 2 years as this constitutes an appropriate time period during which they could remember most details about their experience.

The exclusion criteria included: (i) being able to walk; (ii) having mental disability; (iii) living outside of Montreal. We excluded the candidates who were able to walk. This capacity would inherently remove or compromise the principal challenges we were seeking to address. Moreover, we excluded persons with mental disabilities because this population may not be able to remember or express her or his experiences clearly. Finally, we excluded candidates living beyond the city of Montreal because travel was not feasible for the interviewer.

In total, we conducted 13 semi-structured interviews. After this point we stopped data collection because we had obtained data saturation, meaning that additional data would not improve the understanding of the phenomenon and would simply reiterate what was said in previous interviews (129). “When no new information is forthcoming you have reached saturation point.” (130). It is pertinent to mention that our experience of saturation reflects that of other researchers: according to Guest, Bunce, & Johnson (2006), saturation can be obtained after twelve interviews with a sample of relatively homogeneous individuals (131).

4.3.2. Recruitment

Recruiting participants constituted a challenge, requiring several different approaches. The initial list, derived from the search for members of the advisory committee, was later expanded through the project’s networks.

In order to contact potential participants, we reached out to several organizations and institutions by email and in person. These email messages described my project and its aims, ethical issues and the length of potential interviews. Additionally, I personally visited selected institutions that support people with disabilities such as community organizations providing different kinds of activities for people with disabilities, rehabilitation centers, organizations providing consultations, and the office of students with disabilities in two universities in Montreal. I had several meetings, both with and without appointment, with directors from these organizations.

Additional assistance came from the efforts of the advisory committee members and interview participants themselves. One member published an announcement about my project in one organization’s newsletter and further promoted the project on her radio program. In addition, one of the participants, who is active in an organization related to people with disabilities, arranged for me to work as a volunteer server at a dinner for a group of people with disabilities. There, I had

the opportunity to meet and talk to many people and invite them to participate in the project. Finally, the members of the advisory committee also directly contacted individuals in their networks to introduce our project to the community of people with physical disabilities.

I received a number of emails and phone calls from people who were interested in participating in interviews. I contacted these candidates to confirm that they met the inclusion criteria and to answer any questions regarding the study procedures. If a candidate met the criteria, I organized a face-to-face interview with her or him.

4.3.3. Interviews

I conducted all interviews in English from October 2011 to October 2012. Each participant and I met in a quiet place according to their preference. The setting allowed the participant to feel comfortable to talk and freely express opinions. Because of the issues of accessibility and transportation, our options for the interview location were limited. Consequently, six of the interviews were conducted at participants' homes, seven others were conducted in various places such as participants' workplace (two interviews), in cafes (two interviews), at McGill University (two interviews), and in a community organization (one interview).

As previously mentioned, these interviews were conducted in a semi-structured and informal manner, using an open-ended conversational style. The interview guide designed with the help of the advisory committee, helped structure this examination of the perspectives of people with physical disabilities towards dental services (Appendix C). We intended to design the guide in a way that assisted the participants in recalling their past experiences and to express additional issues that may not have been covered by the questions.

The questions were designed with two principal considerations: their content and form (127). Following productive discussions with one of the committee members, we made an effort to cover a wide variety of issues that people with physical disabilities may face when seeking dental services. Moreover, we deliberately structured the questions in a form and language that participants could easily understand.

This interview guide was further refined two separate times during the process of data collection, following the second and tenth interviews. The final version of the guide includes 6 sections, which cover the following subjects: the process of finding a dentist; making an appointment and transportation; accessibility of the building and dental office; individual oral health; general health problems; economic related issues; and, finally, participants' ideal dentist and recommendations.

Each interview followed a general form. I firstly thanked the participants for collaborating in my project and then I introduced myself to provide a better understanding of my own background. At the same time, I explained my project in a few words and detailed my proposed use for the collected data. Finally, I answered their questions related to the interview process or the project as a whole.

Subsequently, participants signed a consent form in English or French, according to their preference (Appendix A, B). This consent form was agreed upon by the Institutional Review Board (IRB) of McGill University's Faculty of Medicine.

Before beginning with questions, I explained the importance of recording the conversation and indicated when the recording began. This is an essential step for any researcher, as it is impossible to memorize the complex conversations that ultimately constitute the interview data. When transcribing the record, however, it is important to do so verbatim so as to produce a document for analysis that contains the full exchange word-for-word (127).

I began the interview with the following open-ended question: “could you please describe your last dental problem and tell me what happened?" When the participants began to describe a specific event related to the subject, I started to ask more detailed questions to better understand all aspects of the event and their experience.

During the interviews I took notes if I had additional questions or if I needed more clarification from a participant. This enabled me to avoid interrupting the participants and to pose my questions at an appropriate point in the conversation.

The actual order of the questions in the interviews occasionally deviated from that of the guide. For example, when a participant mentioned a new event or experience later into the interview, I might repeat previously-asked questions in order to discover more details about the new event. Sometimes, the participants would misinterpret a question, requiring me to re-phrase its wording in order to elicit a pertinent answer.

During the interviews, in addition to the main questions written in the interview guide, I used two other mechanisms to obtain deeper and more detailed information and to manage the conversation. The first strategy, suggested by Rubin (127), involved repeatedly asking follow-up questions to get deeper information from the participants. For example, one participant stated that dental staff had previously refused to help her to move from the wheelchair to dental chair. Subsequently, I followed-up with questions such as: “what did the dental staff say?”; “how did you feel at that time?”; and, “how did you transfer from the wheelchair to the dental chair?”

The second strategy was the use of probes to “manage the conversation” (127). Probes, both verbal and non-verbal, can be used for multiple purposes: to show that the interviewer is carefully listening to the participant, to keep the conversation focused on the topic, and to examine the participant’s memory and the kind of bias she or he might have. Verbal probes are short, simple questions or comments that do not necessarily contain the subjects that are being discussed.

For example, some of the probe questions that I asked were: “Really?”; “What happened, exactly?”; and, “Oh! There were some stairs!” Additionally, I used non-verbal probes such as actions and gestures that showed the participant that I was interested in hearing more about an event or needed clarification.

In the last minutes of the interviews, after finishing the main questions, I used a check-list to make sure that I had discussed all the planned issues. I read the list in a loud voice to review it with the participant and discussed any parts that had not been previously considered.

After finishing the interview, I turned the audio recorder off and filled out a short questionnaire to collect the participant’s socio-demographic information. This included their age, gender, level of education, and employment (Appendix D). The results of this survey are summarized in Table 3 in the Results section.

Finally, at the end of the interview, I asked the participants if I could contact them again in case I had additional questions and if they were interested in the results of the study. I then thanked them for their time and for sharing their experiences with me. Normally, the interviews took about one hour but in a few cases lasted up to two hours.

4.4. Data Analysis

Data analysis was an ongoing process that started after the first interview. I began by transcribing the discussion verbatim immediately after each interview. It was a time-consuming task that took approximately 2-3 days of work per transcript. Nevertheless, this was a useful step as it helped me to familiarize myself with the data (132). In this process, I used symbols to make the text clear and smooth. For instance, the non-verbal actions of the participant were described in parentheses such as “(laughs)”. Refer to Table 2 outlining the symbols used.

Table 2. Symbols used in transcripts

...: Indicating when the participant did not complete her or his sentence.	**Single Capital Letters:** Indicating names of additional people and places mentioned in the interview, shortened to retain anonymity.
???: Indicating when I am unsure of the meaning of a word.	***Italic*s:** Indicating when participants quote other people.
( ): Indicating a non-verbal gesture or action on the part of the participant.	**[ ]:** Indicating words that I added in transcription to make the text more coherent.

Additional steps were taken to ensure the ethical management of the interview data. All the audio records and transcripts were saved as computer files. In order to ensure confidentiality, I removed the names of the participants from both transcripts and the socio-demographic questionnaires. Each interview and its participant were identified according to their order in relation to the other interviews. These numbers were then used to code the transcripts, socio-demographic questionnaires and consent forms of each participant. Furthermore, care was taken to ensure that the transcripts and socio-demographic questionnaires did not contain names and information that might identify participants. The consent forms, which do contain the names and identification numbers of the participants, are kept in a locked cabinet in the Oral Health and Society Division of McGill's Faculty of Dentistry.

After completing the first interview transcription, the resulting data were immediately analyzed via an inductive thematic method inspired from Braun and Clarke (133). As the researchers note, "thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail," (133). The inductive approach is "a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions," (133). This meant that I did not have a pre-established list of codes before I began the coding. All codes emerged and, as Braun and Clarke recommend, were "explored" from the data (134).

In the process of coding I firstly read the transcripts line by line and marked the parts of the text in which I recognized a concept, event, example or theme. This part of the text could be a word, phrase, sentence or paragraph and is otherwise called a "unit of meaning" (135). In the margins of the text, I wrote a short note describing what each unit of meaning was about.

In the second phase, I used my notes to choose the units that I thought could help me better understand my research question. Following Rubin's method, I coded those units with brief and informative names (127). As Miles and Huberman describe, "codes are tags or labels for assigning units of meaning to the descriptive or inferential information compiled during the study. Codes usually are attached to "chunks" of varying size words, phrases, sentences or whole paragraphs… [and] are used to retrieve and organize the chunks…" (135). Moreover, as Rubin notes, "each unit of analysis might be linked to several codes." (127).

Coding was an iterative-recursive process. Although most of the codes were established by the fourth interview, new codes continued to emerge throughout the study. I organized my notes through a list of codes and their definitions in table form to facilitate their reference.

At the third step in the process of coding, I looked for relations between codes, grouped and consolidated them when appropriate. I endeavoured to choose the most comprehensive phrase for each category to best represent all the codes fitted together under the title of the theme. For example, the code "costs" was joined with "insurance" under the category of "financial issues". After each new interview, I revised the table of codes, adding new ones and merging codes that represented similar units of meanings.

During this step I also organized the units of meanings. As Miles and Huberman explain, "the organizing part will entail some system for categorizing the various chunks, so the researcher can quickly find, pull out and cluster the segments relating to a particular research question, hypothesis, construct, or theme.

Clustering, and display of condensed chunks, then sets the stage for drawing conclusions." (135).

Over the course of processing, I merged the texts of the 13 interviews in a single word document. After the first four interviews, I made a word document called "All Interviews", containing all the emergent codes. Then, working from each subsequent interview transcript, I copied and pasted all texts (units of meanings) related to a specific code to this document. In this way, I collected all texts assigned to a single code together, thereby granting me easy access to all interview texts related to a code. This document evolved and changed with the developing names and scopes of the codes.

For example, Figure 3 is a small part of this word document showing those passages of different interviews where the participants talked about transportation. The participant's number of origin is signified by (Int #). It should be mentioned that I had to modify this document as I modified the codes.

Figure 3. Sample of document containing all 13 interviews

9) C 9: Transportation

(Int 1) It's a small town I was just able to go like maybe 5 blocks from where I was. Because it's in northern [province B].

(Int2) It depends. I can go by walk, I don't know if you saw it when you got out of the train

(Int2) It's on other side of the track, It's like 10 minutes walking, I'm not walking but whatever…. wheelchair.

(Int4) adapted transport.

(Int5) how do you go to the mall? Adapted transport.

(Int5)...it's in a mall because otherwise you know you don't wanna put your transport too early and have to book another one because your appointment takes longer so you're stuck waiting in the entrance and now at least when my appointment goes quicker then I can go and shop around a little bit.

(Int6) How do you go to the mall? Adapted transport.

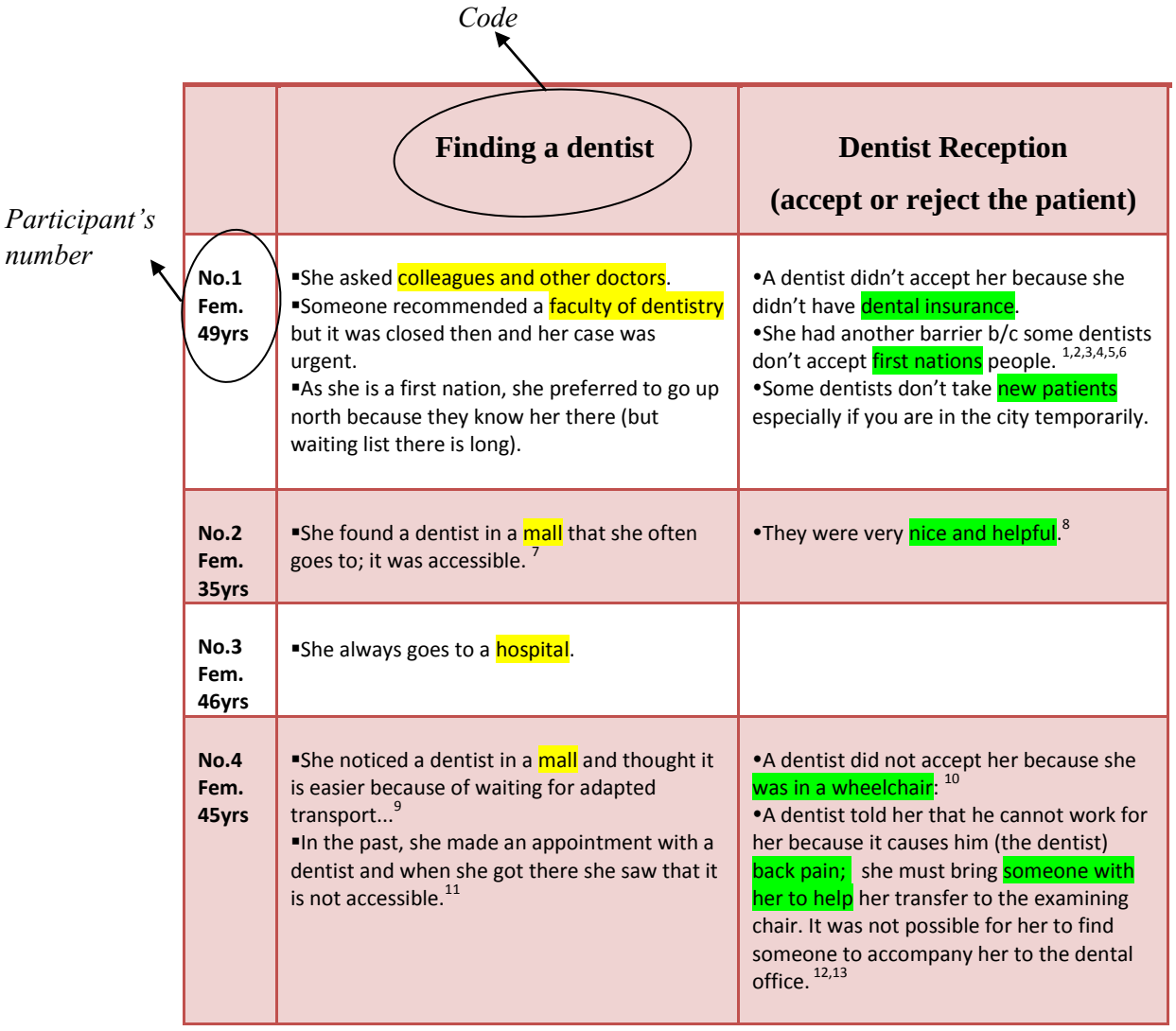
.....

During the preliminary stages of the project, the codes were categorized into simple, logically-related groups such as physical, dentist-related, financial, and time-related barriers. As data collection progressed and new codes emerged, we explored profound relations and patterns among codes. Consequently, we regrouped the codes and categories into two main groups: firstly the codes that represented the facts related to oral health and the individual oral care of people with physical disabilities and, secondly, the codes that referred to various challenges that individuals with disabilities faced in their dental care pathway.

In the fourth phase, as per Miles and Huberman's recommendation, I made matrices to display and summarize the data by "condensing and distilling it to be able to see the data as a whole. The chance of drawing and verifying valid

conclusions are much greater than for extended text, because the display is arranged coherently to permit careful comparisons, detection of differences, noting of patterns and themes, seeing trends, and so on," (135). Because of the considerable size of the data set, four matrices were required to summarize it. Figure 4 is a sample of the matrices.

Figure 4. Sample of matrices containing all 13 interviews



	Finding a dentist	Dentist Reception (accept or reject the patient)
No.1 Fem. 49yrs	▪She asked colleagues and other doctors. ▪Someone recommended a faculty of dentistry but it was closed then and her case was urgent. ▪As she is a first nation, she preferred to go up north because they know her there (but waiting list there is long).	•A dentist didn't accept her because she didn't have dental insurance. •She had another barrier b/c some dentists don't accept first nations people. [1,2,3,4,5,6] •Some dentists don't take new patients especially if you are in the city temporarily.
No.2 Fem. 35yrs	▪She found a dentist in a mall that she often goes to; it was accessible. [7]	•They were very nice and helpful.[8]
No.3 Fem. 46yrs	▪She always goes to a hospital.	
No.4 Fem. 45yrs	▪She noticed a dentist in a mall and thought it is easier because of waiting for adapted transport...[9] ▪In the past, she made an appointment with a dentist and when she got there she saw that it is not accessible.[11]	•A dentist did not accept her because she was in a wheelchair: [10] •A dentist told her that he cannot work for her because it causes him (the dentist) back pain; she must bring someone with her to help her transfer to the examining chair. It was not possible for her to find someone to accompany her to the dental office. [12,13]

As shown in Figure 4, the number, gender and age of each interviewee was noted in the first column, whereas the codes were in the following columns. Besides, each row corresponded to a participant. Each cell in the matrix therefore represented a specific participant and a specific code that arose from her or his interview. The cells were populated by reviewing all the quotes of a given participant in relation to a given code. For example, I began by reading all of the remarks from participant number 4 in regards to "dentist reception" and then wrote a summary of the data in bullet point form in the related cell. Additionally, I inserted whole quotations related to the codes in the form of footnotes, at the bottom of the matrices. The matrices thus prepared, I was able to proceed to the final stage of the analysis.

The last step concerned the interpretation of the results and the production of a report about the perspectives, experiences and barriers that participants described in the interviews. Interpretation was an extension of code creation; the report was initiated only after data collection and coding were finished. In this phase, we produced a narrative text describing the main contents of matrices.

4.5. Ethical issues

Several measures were followed to ensure that the treatment of participants in this project met the highest ethical standards. Approval for all actions was obtained from McGill University Faculty of Medicine's Institutional Review Board (IRB) prior to their initiation. The IRB study number for this project is A05-E36-11B.

The consent and autonomy of participants was respected throughout the research process. Each participant read and signed her or his consent form, available in both French and English, before the start of the interviews. I reiterated that if a question made a participant uncomfortable, he or she need not respond. This did not happen in our interviews. Furthermore, participants had been informed that they had the right to withdraw from the study at any time.

Efforts have been taken to ensure that the identities of the participants remain confidential. Audio records of interviews, which may contain revealing names and locations, were destroyed once their content was transcribed. Moreover, the resulting transcripts of these interviews and participants' socio-demographic questionnaires do not contain any otherwise identifying information. The records containing the participants' names and telephone numbers have continually been kept in a secure location. Only researchers in this project had access to the records. These records have been retained solely for use in potential follow-up interviews and to share the results of the project with the participants upon the completion of this study.

5. Results

This chapter presents the analysis of the interview data. The majority of subjects discussed the difficulties and challenges that they faced when in need of dental services. We classified these challenges into 11 diverse categories including availability of an accessible clinic, first contact with a dentist, treatment session and financial barriers.

In addition, during the interviews, participants referred not only to challenges but to other topics as well. These topics are pertinent in that they elucidate participants' perceptions of their oral health conditions, oral hygiene and the way they preserve their oral health. Due to their importance, these complementary topics are also presented here.

In the following paragraphs, we will start by a description of our sample, then present participants' perspectives on oral hygiene and oral health; we will then describe in detail the challenges that they face.

5.1. Part one: Description of the sample

As shown in Table 3, we interviewed 13 people, nine women and four men, with physical disabilities who used a wheelchair. The majority of the participants were between 30-64 years old and used electric or manual wheelchairs. While the cause of disability for four participants was an accident, the other individuals (9 out of 13) had diseases that resulted in disabilities. Among them, three persons had cerebral palsy and two had arthritis. Only four participants were in paid employment; all but one of those not in paid employment nonetheless did volunteer work.

Table 3. Demographics of participants

Characteristics	Categories	Number of participants
Gender	Women	9
	Men	4
Age, years	18-29	1
	30-49	6
	50-65	6
Occupation/Income source	Full-time	3
	Part-time/casual	1
	Unemployed/no volunteer work	1
	Unemployed/with Volunteer work	8
Reason of disability	Accident/spinal cord injury	4
	Disease	
	Arthritis	2
	Cerebral palsy	3
	Neuromuscular diseases	1
	Muscular dystrophy	1
	Spinal meningitis	2
Type of wheelchair	Manual wheelchair	3
	Electric wheelchair	10
Time in wheelchair, years	Less than 10	2
	10-20	3
	21-30	6
	31-40	1
	More than 40	1
Dental insurance	Private insurance	4
	Public insurance (welfare)	9

5.2. Part two: Oral health and individual oral care

5.2.1. How participants perceive their oral health

5.2.1.1. The mouth as third hand

Interestingly, many participants explained that they used their mouth in replacement of or in addition to their hands. One of the participants referred to her mouth as her "third hand" because her right hand was not functional and she used her mouth to compensate in various useful ways. Also, some participants started to use their mouth more and more while their disease was progressing:

> *I do everything with my mouth now, I put everything in my mouth now, and I do everything with my mouth now. Because it's like my third hand, because I don't have the usage of my right hand, it's all paralyzed. My left hand is working a bit but not my right, so I do a lot of things with my teeth, you know I'm grabbing things, I'm holding things so it's very important that I take very good care of my teeth. [Int.2]*

> *Of course, every catheter I open up, I have to pull on the paper and the material is like... I'll show you. It touches our teeth, often it is not alcohol but... I really, really try to open up as many things as possible with a knife in the kitchen because my fingers used to be stronger but now I use my mouth and teeth more and more. [Int.7]*

Some participants, whose hands were not paralyzed, used their mouth to hold objects since they needed their hands to move their manual wheelchair. When operating the wheelchair by hand, they used their mouth to grab things:

> *Yes, sometimes I grab my cell phone with my mouth... we all do that; I saw yesterday, I was looking at the book of Paralympics, one of the girls, she is a Paralympics athlete in a manual wheelchair and she plays basketball in a wheelchair. I've seen the photo [where] she was grabbing in her mouth one of the wheels of the wheelchair... because she had 2 [wheels] so she had put one against her chest and she was grabbing one. I do things usually when I have many things on my lap and I'm running my wheelchair. [Int.9]*

I do [use my mouth as a third hand] for a lot of things: when I carry a plate I use both hands and I'll put my forks and whatever in my mouth to carry it. I carry a lot of things and open a lot of things like my pill bottles. Yes, they're kind of our third hand. [Int.5]

Yes, sometimes, not as much as other people because I have one hand but some things require two and I can like open a bottle with my mouth or hold something when I have to push my wheelchair. [Int.6]

The participants used their mouth in various ways and circumstances; for example, when using a catheter, carrying a cell phone or a book, opening a bottle of medication or even holding empty boxes when moving. The more their hands were weakened or paralyzed, the more they tended to use their mouth:

[…] to have good teeth for me is essential because I need my mouth to actually do everything, so I'm trying to keep as many [tooth] as possible in my mouth! [Int.8]

All participants who used their mouth as "third hand" mentioned that they tried not to damage their teeth. However, some of them reported injury as a consequence of using their mouth to do things.

In contrast, a few participants did not use their mouth as a "third hand" despite completely paralyzed hands. These participants relied on an assistant or a family member to help them with their daily activities. One of them explained that she was very careful with her mouth and teeth because dental services are very expensive. She used her mouth to hold things only when engaging in adapted sailing.

5.2.1.2. Importance of oral health

The majority of participants considered that oral health was important for several reasons. First, good oral health enabled the use of the mouth as a "third hand". Participants did everything with their mouth; a participant explained that after her

accident and her paralysis, she had been forced to use her mouth more than before. Thus, she thought that she had to pay more attention to her oral hygiene and preserve her oral health:

> *Now I am more aware because I'm using my mouth more and my teeth of course. [Int.2]*

The second reason for valuing oral health was appearance. One participant explained that her dental appearance was important because she was teaching and was working with the public. Another stated that she would do whitening for one of her composite fillings; she was not, however, interested in additional aesthetic treatments:

> *Yeah, taking care of my teeth is important to me but I wouldn't go to extremes. I did ask about the whitening but because they've put something on my two front teeth [...]. [Int.4]*

Moreover, some participants mentioned that teeth are very important when they smile because they are the first thing that people see. They believed that people judge social status, background and personal care from your teeth. Yellow or crooked teeth would discourage social interaction:

> *The teeth are very important; they are the first thing you see when you smile. Somebody looks at you, if you have crooked teeth, or if you have yellow teeth, or if you have a hole, then people immediately judge your social status, your hygiene, the type of person you are, and right away they avoid you or go away; they don't even talk to you. [Int.8]*

Nevertheless, participants did not emphasize aesthetic procedures (e.g., bleaching the teeth). For example, a participant mentioned that although her dentist recommended whitening her teeth, she had more important needs:

> *She [the dentist] wanted to do a whitening on this tooth and I said, "you know, I don't want to do that, it's only for appearance and I'm not ready to put money on that. I'd rather, you know, put everything else in place*

and, you know, put money on my daughter or whatever, on what she needs, before doing that". [Int.2]

The third important reason for maintaining oral health was economic. A participant explained that she took care of her teeth because the costs of dental services are high and she didn't want to spend a lot of money for dental treatments:

Oh yes, even if I don't have insurance [...] I think it's very important and furthermore because I do everything with my mouth now... so it's very important that I take very good care of my teeth. [Int.2]

Because now I really don't want to see the dentist too often so I'm [...] taking care of my mouth. [Int.13]

5.2.1.3. Change in oral health since using a wheelchair

While some participants reported changes in their oral health status after they started using a wheelchair, others did not. Several participants mentioned the occurrence of gingivitis and tooth decay in the first years, but some also explained that, after several years, their oral health had improved. They explained that, in the first years, their hands and arms were paralyzed but after rehabilitation they learned how to use their hands and arms despite difficulties. In addition, the use of an electric tooth brush had contributed to improved oral health:

Well, at first yeah, because I didn't have any movement in my hands for almost a year so I had to... someone had to brush my teeth. It was a really awful experience seriously because nobody except yourself can do it right. So, yes, it was something that was frustrating and difficult to manage. [After one year you could?]Yeah, I was able to do it myself again. [Int.6]

5.2.2. How participants maintain their oral health

5.2.2.1. Individual oral care

Because of their physical conditions, the majority of the participants experienced difficulties in maintaining their oral hygiene independently. Most participants needed the help of an assistant, a partner or other family member to brush their teeth:

> *That's my dear [husband] that brushes every night, so electric [toothbrush], we do a really good job because I can't do anything myself and can't use my hands. [Int.13]*

While some participants brushed their teeth 2-3 times a day, those with less manual dexterity experienced difficulty in brushing and flossing. Consequently, they devoted less time to brushing. For instance, a participant explained that she only brushed her teeth a couple of times a week because she had difficulty in using her hands and keeping water in her mouth. Another said that brushing was "almost a challenge" for him.

Participants also experienced difficulties with flossing. For instance, because of arthritis, a participant said that flossing her teeth was very difficult for her, even with dental floss holder:

> *People keep telling me "you should floss more" but you know, it's difficult even with the fork. [Int.5]*

Unfortunately, as described above, when disease progressed and disability became more severe, the ability of the participants to maintain their oral health decreased. Participants who became gradually less mobile recognized reaching a point where they were not able to brush their teeth as well as before:

> *It's [brushing] more and more difficult. I have an electric tooth brush and it's getting harder and harder. [Int.8]*

Yet several participants explained that this process was somewhat reversible. One or two years after the accident that caused their disability, certain participants reported partial recovery and improved function of hands and arms, allowing them to improve their oral hygiene:

> *At the beginning, the first year, I wasn't able to brush my teeth by myself because I was still paralyzed […] so I didn't brush my teeth. I had gingivitis but it was ok. [Int.2]*

5.2.2.2. Other limitations of body

Many participants had other physical limitations in addition to not being able to walk. These affected participants' oral hygiene and caused difficulty in receiving dental care services. Here, we will describe different kinds of physical limitations that presented obstacles to oral hygiene, and we will explain how participants overcame these problems and managed their oral hygiene.

While the most common problem among the participants was paralyzed hands and arms, the dentist or hygienist was not necessarily knowledgeable about common physical conditions of people with disabilities. Consequently, they ended up disappointing the participants because they asked them to perform tasks that they were not able to do. For example, a participant with arthritis, who could not use her hands properly, explained that a dental student made her feel inadequate upon exhorting her to floss her teeth:

> *They are not that used to limitations […]. In real life I'm not gonna start flossing every day. [Int.5]*

> *They tell me to floss more and I tried to tell them that it hurts and that it's not easy. They kind of still try to push it on me. Last time I went, I really, really felt bad and I kind of started crying a little bit because the student made me feel really bad about not being able to floss easily. [Int.5]*

Another limitation was related to participants' ability to open or close their mouth. Some diseases such as arthritis and muscular dystrophy progressively affect these functions. In addition to increased difficulty in taking care of oral hygiene, these limitations complicate the dental treatment, as we will discuss in subsequent sections. For instance, a participant with muscular dystrophy stated that she had difficulty brushing. Despite this, a dental assistant insisted that she must brush her teeth regularly. This dental hygienist seemed insensitive to the participant's difficulties to keep water in the mouth for tooth brushing:

> *It's like smaller every year. Not every year but little by little smaller as my arthritis is progressing, I've never been able to eat a hamburger but it's ok. For big pieces it's harder to chew or biting likes an apple, it's really hard. [Int.5]*

> *One time I had a dentist she was like tooth assistant, [she always said] "you got to wash your teeth; you got to wash your teeth" I told her I have hard time, I can't do it but she doesn't understand that, you know? She didn't understand my situation, you know? I cannot do like you do, every day, 3 times a day. It's impossible, you know? She doesn't understand. She was just going on and on and on and on. You know? [Int.3]*

Another serious but rare issue in participants with cerebral palsy, was dysphasia; a participant with this problem was very sensitive to instruments or foods in his mouth. He was not able to eat certain foods with a liquid or hard consistency as they caused coughing. To prevent this, his assistant used a sponge and regular tooth brush for cleaning his teeth instead of an electric tooth brush.

5.2.2.3. Participants' solutions: maintaining good oral hygiene in spite of limitations

Participants had different solutions to overcome their limitations. Most participants reported that the use of an electric toothbrush significantly contributed to improved oral hygiene. Some said that before using an electric

toothbrush, they required a lot of fillings or professional cleanings, but that their oral health improved with the use of the electric brush:

> *Before I had the electric toothbrush, I didn't realize that it would make a difference and it did make a big, big difference because before, they would always tell me that my teeth were ok but they did not… you know, they would work a lot to clean them and now it's really easy. [Int.4]*

> *Before because I could not brush as hard as electric tooth brush, I would have to go back and have some fillings, so after my accident I had a few fillings done because my hygiene was not as good. Because I couldn't work with the tooth brush -the regular tooth brush- well enough. But ever since the electric one I have no need for fillings, I just go for regular checkups and in the last years the only thing we need is to replace old fillings. [Int.4]*

Some participants described using a bracelet to hold the toothbrush, putting the handle of the tooth brush in the bracelet because of paralyzed fingers:

> *Ever since the beginning I would put a regular toothbrush in my bracelets that I use, the same bracelets that I use to hold my fork, because my fingers don't move. (Shows the bracelet) I used to put the toothbrush in here and brush my teeth, but of course I can't move my arm in every way like I do with an electric tooth brush; now the electric tooth brush just has a handle that we added to it, so it's easier because the electric tooth brush is more powerful, so I don't have any problems with my teeth anymore. [Int.4]*

An electric water pick was another device used to help oral hygiene. As mentioned before, due to their physical limitations, some participants were unable to brush their teeth by themselves and asked for assistance. However, tooth brushing was not an easy task either for the participant or for the carer. A participant decided to buy an electric water pick so that the others who did the brushing for him would not hurt him:

It's a lot more difficult, so it's almost an effort to motivate myself to brush my teeth but I know that if I don't do it, it's gonna be worse. It's just so much work; you know I do the minimum. [Int.8]

It's more and more difficult. I have electric tooth brush and it's getting harder and harder so my next investment will be electric water pick style tooth brush so if somebody else has to brush my teeth, they can't hurt my gums with water, which to me is very important. Somebody else can have all the best intentions but they don't know and they might brush too hard and then do more harm than good. [Int.8]

5.3. Part three: Dental care pathway

5.3.1. Challenge 1: Finding an accessible dentist

Finding a dentist was the first barrier that participants often faced when in need of professional services. Most of them had a family dentist at the time of the interviews, but finding their dentist had not been easy; for some, it had taken up to two years to find a dentist.

Participants stated several barriers in finding a dentist. The first was the lack of a reliable source of information to provide the coordinates of accessible dental clinics:

That's the hardest part, no where you can ask or go on the internet to see a directory of dentists let's say in Montréal and say with the specification 'wheelchair accessible'. [Int.8]

Thus, the majority of the participants tried alternate networks to find accessible dental clinics. Some of them asked colleagues, friends, family members or health care givers and some others searched their neighbourhood with their wheelchair or by car. The others searched the internet and called the dental offices to ask if they were accessible.

The second difficulty that some participants faced was incorrect definition of accessibility by dental staff. On the phone, some dental staff had told participants that the clinic was accessible; but when they went to the location, they discovered that there were one or two steps, which made the building inaccessible. As one of the participants said "it was accessible with one step!":

> *When I got there, I couldn't get into the office. There were steps. As I remember there were 5 or 6 steps or something like that.... [Int.4]*

> *A lot of them [staff] said "oh yes we are accessible". They only have one step but that is not accessible. You see! A lot of people don't understand. You can't get mad at them because they're just ignorant, but it makes me mad after a while [I think] "god we can't find a doctor because it's not accessible!" we can't get a dentist because we have so much trouble getting one. [Int.7]*

In summary, only a few participants were able to find an accessible dentist right away. It occurred to a participant who was working in an association related to people with disabilities to find a dentist very fast. His colleagues recommended a dentist sensitive to conditions of people with disabilities. The social worker of a second participant recommended a hospital that provided short term clinics for treating people with disabilities.

Sometimes the process of finding a dentist was so frustrating that participants gave up searching. For example, a few participants were not satisfied with their current dentists and wished to find a better one; but because of the exhausting "process" of finding a new dentist, they had postponed it:

> *It would be like a' process' to find a new one [...] that is close, who will be accessible. At least this one I know there is an elevator and whatever, so, yeah we'll see. [Int.5]*

5.3.2. Challenge 2: Being accepted by the dentist

The next challenge after finding a physically accessible dental clinic was acceptance by the dentist. Sometimes the participants found an accessible clinic but during the first contact with the dental office, some participants were rejected. They were refused by dentists for different reasons, but the main reason was related to their disability.

According to some participants, dentists usually refuse to offer treatment for a person in a wheelchair. A participant stated that one dentist didn't accept her because "he did not like the fact that I was in wheelchair". Another participant who was disappointed because of being rejected by a dentist stated that some people think that people with disabilities had no brain or hygiene. Also, he believed that sometimes people who don't have anybody with disability around them are scared of people with disabilities. Another participant believed that some dentists made excuses not to accept people with disabilities, for example they said that their office was not adapted:

> *He didn't like the fact that I was in a wheelchair. I don't know but he just refused to work on me, he said "I don't do people with disabilities" or something like that. It's offending and in my case I don't let anything put me down but I'm sure... somebody else could be [they would say]: "I'm not going to the dentist anymore because of that". [Int.4]*

Another reason to be rejected by the dentists was related to private dental insurance. Some participants stated that some dentists did not accept them because they did not have dental coverage:

> *If you didn't have insurance, they wouldn't take you right away. [Int.1]*
>
> *I didn't have dental coverage. I didn't have private dental coverage. He saw that I was first nation and he said I don't wanna… you have to go. [Int.1]*

Other reasons for being rejected by dentists included being on welfare or being First Nation. These situations, which at times were compounded in a participant, created even more discrimination. A participant thought that she was rejected for two reasons: (i) she did not have any dental coverage; and (ii) she belonged to a First Nations people. Similarly, a participant had to change his dentist, despite their good relationship, because the policies of the clinic had changed and they no longer accept payments from welfare:

> *Dentist office can accept any kind of payment and if they do accept government insurance for people that are on welfare, then they have to accept the prices that government will pay them for dental checkups, x-rays and cavity repairs etc. some dentists don't want that, they just take private insurance or they take cash of course, so it's a double challenge to find [a dentist]. [Int.8]*

On the other hand, some participants had been rejected by dentists because of physical limitations other than using a wheelchair. A person who had arthritis and could not open her mouth wide enough had a negative experience. Her dentist had told her that if she had a problem in her back teeth, she would not repair her tooth.

Sometimes dentists set conditions for acceptance: a participant who had paralyzed feet and arms had difficulty in transferring to a dental chair. She explained that she preferred to stay in her wheelchair but her dentist had told her that if she did not bring someone to help her transfer, she would not treat her:

> *I had to change [the dentist] because the other one said that taking care of me was giving her too many back pains and I had to bring somebody with me to transfer me into the chair and that was complicated. [Int.4]*

5.3.3. Challenge 3: Appointment organization and transportation

Participants faced problems in using adapted transport and in making dentist appointments. In most of the cases, they explained that an unexpected change in appointment time caused problems in transportation and vice versa.

One problem relating to appointments was limited spaces in university clinics that provide free dental services for people with disabilities. The participants who were planning to go to those clinics had problems in making appointments:

> *So I'll check to get in but there are limited places, you know, so I think they take about 50 or let's say 100 people; there is like 500 people that want to get in. [Int.2]*

As mentioned, the majority of the problems with appointments were related to adapted transportation. Most of the participants used adapted transport to go to the dental clinic and few of them had their own adapted van or car. For most participants, organizing transportation was challenging and sometimes impossible. To use adapted transport participants must carefully arrange the time of appointment with both the dentist and adapted transport.

Participants must inform adapted transport of their time of departure and return 24 to 48 hours in advance. Although it is possible to rearrange the transportation time 1 to 2 hours in advance for medical and other important appointments, participants preferred to make the appointment earlier. Arranging for transit on short notice was time consuming and complex, requiring more time on the telephone and an increased risk of late arrival of the adapted vehicle. One of the participants stated that it was the participants who should be flexible to adapted transport not the other way around:

> *Yeah, only in medical ones you can: doctors or whatever […] sometimes they keep me 10-15 minutes on the line and then they get back "ok Mr. C, they'll be there in 45 minutes." [Int.12]*

When the adapted transport was cancelled without notice, the participants explained that they were the ones who had to answer to the dental office, not the transporter. A participant reported that, when she cancelled her appointment repeatedly because the adapted transport did not show up, the receptionist blamed her:

> *[Translation] adapted transport did a mistake in the time of appointment. So I called them [the dental office] and said "Excuse me", when the receptionist called me she said "you have cancelled for 3 times" when I went there I said "Look at me I don't have the possibility... sometimes there is no choice but cancelling". [Int.10]*

Participants also mentioned that the length of treatment sessions was not easy to predict: when the dental visit took longer than expected, the participants missed their return transportation and had to arrange alternate transportation. When the dental visits took less time than expected they had to wait in small waiting rooms or in hallways:

> *That was a problem because the first time I went to my regular dentist, I booked for an hour and it took like two and half hours. So I had to kind of make arrangements so that they pick me up later. And then the second one I was just [thinking] takes as long because I had a filling and of course it took like 20 minutes and I was out, so again I had to call and make arrangements and [they said]"we're gonna pick you in an hour" and I had to spend an hour sitting in the waiting room for nothing. [Int.5]*

Both conditions were inconvenient for participants; but most of them preferred to put their return transport appointment for a little later than they thought they would need rather than missing the transport and making another appointment:

> *You have to make sure just minimum 48 hours in advance and then you give them the time of your appointment but then time of your return if I know it, I tell them but I also add on an extra hour just in case. [Int.12]*

Participants with less physical limitations had more choices for transportation. For example a participant who was able to transfer by herself could take a taxi, but she added that the choice of taxi driver was important:

> *Of course the driver has to know how to take out my wheelchair and put it in the cab and help me take my crutches, and see if I need anything else. But I know the others, the ones that are tetraplegic or quadraplegic they cannot go [by taxi]. [Int.9]*

Finally, some participants attenuated the problem of transportation by being able to find a dentist close to their house and riding their wheelchairs there. This solution, however, had its own problems because sometimes sidewalks were not safe for a wheelchair:

> *I can even ride there with my wheelchair, it's not too far, it's on the corner [...] it's like 10 min away, 15 min the most because I can't go fast because of cracks on sidewalks and streets there, but it's not that far so I don't have to take the adapted transport, so it's good. [Int.7]*

5.3.4. Challenge 4: Entering the building

5.3.4.1. Ramps and elevators

The most obvious problem related to the buildings was the absence of ramps and elevators. Most participants described unpleasant experiences related to this issue. For example, a participant went to a dentist for 15 years before her accident. After the accident, she had to cancel her appointments because the building did not have elevators:

> *[I called them I said] I had an accident and I don't think I'll be able to go again at your place and they said why and I said I don't think I'm gonna be able to walk again and they said come on! you know and I said no I don't think I'm gonna walk and you don't have any elevators so I'll cancel and I'm sorry but I think you're gonna lose me as a patient and I was sorry, I remember I was very sorry to make that [call]. [Int.2]*

Similar problems were reported by other participants. While they were happy with their dentists and hygienists, they had to replace them because their dentists moved to a building that did not have elevators and ramps:

> *It was still accessible and then after that they moved to another building [...] then she wasn't accessible anymore. [Int.12]*

> *I believe God really watched on [over] me because when I moved, my dentist also was moving into her own practice and had to tell me that sadly, she was going on the 2nd floor with stairs and you see the lord provided that when I moved, I would find another [accessible dentist]. [Int.13]*

However, sometimes when there was only one step, the participants were able to enter the dental office, although this is only possible for participants using manual wheelchairs because these wheelchairs are lighter than electric ones. Indeed, even in a manual wheelchair, the participants needed help to go up the stair.

5.3.4.2. Entrance and doors

Accessibility of buildings was not limited to the availability of ramps and elevators. Even though some buildings seemed accessible at first glance, the narrowness of entrances and the heavy weight of doors made entering difficult. One participant stated that the entrance of her clinic's old building was narrow and that she could not fit and push her wheelchair there. Thus, she needed someone to help her open the door and push the wheelchair through the entrance:

> *Sometimes even though it's like accessible place, the door does not open properly, you know? I don't know who ever decides these places for wheelchairs! [Int.1]*

> *It was how you say that: kind of narrow because they don't make... that was like an old building and I just barely fit with my chair. So I couldn't push. So someone had to push me because the doors were just standard doors like for a normal person. [Int.1]*

Another participant reported that, unable to enter the building, she had to call the staff by phone to come and open the door for her. The reason was the heavy entrance doors, which were not automatic; she was not able to push her manual wheelchair and hold the door at the same time:

> *If the door is too heavy, I don't know, I could call the secretary: "I'm here can you please come and open the door?" something like that, yeah. I have to have a backup plan. [Int.5]*

As a result, in addition to other considerations, some participants chose a dental clinic in a shopping mall or in a hospital for the accessibility of buildings in terms of entrance, elevators and hallways.

5.3.5. Challenge 5: Moving inside the clinic

Another physical barrier related to buildings was small spaces. Narrow hallways, small waiting rooms and washrooms made circulating by wheelchair a difficult task and sometimes impossible.

Hallways:

Participants complained about narrow hallways, which render movement difficult in a wheelchair, especially when other people are present in the hallway. As one participant explained, in big and crowded dental offices, narrow hallways were an obstacle:

> *It's a big dental office so there are a lot of offices [...] when someone is coming, they go back because there is no room for 2 of us: I'm on the chair and they are walking and there is no room. [Int.7]*

Waiting rooms:

Small waiting rooms represented another physical barrier. Participants reported that the waiting room of some clinics was so tight that their wheelchair did not fit in it and that consequently it was impossible for them to wait there. One person said that she had to wait in the examination room or wait outside of the clinic. The disposition of the furniture was another issue mentioned by participants: even in large waiting rooms, the furniture sometimes rendered the waiting room

inaccessible. In this situation the staff had to move some furniture to make room for the wheelchair:

> *In the waiting room: they have 3 chairs and they have the counter there and I only have like space for the legs of the persons that are there, my chair and someone that is standing on the counter and there's no more space. So I don't have any space to be, so I cannot even be in the waiting room, I have to go out or I have to go in, so it's not pleasant. [Int.2]*

Washrooms:

Washrooms were another space that was not adapted in most dental clinics. Bathrooms seemed very important for the participants: as many used adapted transportation, they were out of home for a long time and eventually needed to use the washroom. Unfortunately, washrooms were often non-adapted to their needs, which made the situation stressful for them:

> *The bathroom is very important because most people with limited motility have to take the adapted transport and how long you're gonna be from home and how long is gonna be the transport and just the stress of that they aren't able to use the bathroom. [Int.7]*

5.3.6. Challenge 6: Interacting with the dental staff

5.3.6.1. Dentists and their staff

In all stages of their dental care pathway, the attitudes of the dental professionals could deeply affect the participants. While some of them reported positive experiences with dental professionals, others reported negative interactions. First, we will describe some positive experiences and then negative ones.

Some participants believed that in recent years the awareness of dental professionals about people with disabilities had increased. As a result, their experiences were better than 10 to 15 years ago. Some dental professionals had positive attitudes and left a very good impression on participants. The participants

used words like “patient”, ”positive”, ”helpful”, ”flexible”, ”understanding” and “polite” to describe their dentists or the staff:

> *She’s really nice and even the whole staff is really, really nice and understanding and trying to make it as easy as possible on me. [Int.4]*

On the other hand, some participants mentioned some negative experiences with dental staff. For example, a participant stated that the receptionists ignored him when he entered the office; he had to signal his presence by knocking the counter:

> *When they were opening I went inside and [I said to myself] “ok maybe they’re ignoring you, they’re busy”, so I waited 5-6 minutes then I go (imitating knocking on the counter) [I say] “excuse me please tell Dr. D that I’m here”. [Int.12]*

Some participants explained that dental professionals tended to discriminate against people with a physical disability. One participant explained that when he goes to the dentist with another person, who doesn’t use a wheelchair, the staff first talk to the person who is standing up, not him. In this situation, he said that he would wait and if they didn’t notice him or didn’t pay attention, he would start to communicate:

> *when I’m accompanied by you or someone, you know, they are talking to the person standing up rather than looking at me first, so I have to stay there, I know, so I’m there, and then I look up and then I introduce, you know, you have to give the fraction of a second to them, I just wait and see how long it takes, if I see it takes too long, I say ”alright I’m here too, hello”. [Int.12]*

Another participant mentioned that a hygienist had prejudices about people with disabilities. As the participant explained, this hygienist had told her that she should stay in a center (for disabled people) and it had offended the participant. In the same clinic, as described before, the receptionist blamed this participant

because she had cancelled her appointment 3 times because of problems with adapted transport:

> *And she said to me. Je le dis en français: "vous voulez pas rester dans un centre? [Don't you want to live in a centre for people with disabilities?]". You know I am in a wheelchair but I can stay in my apartment. It's not her business. Oh my god. It's harm to hear the parole, difficile. I decide to change. I'm going change my dentist. [Int.10]*

5.3.6.2. Counters

The majority of the participants reported problems with counters that were too high. When using a wheelchair, the height of the counter made it difficult to see the dental staff and therefore complicated interaction and paperwork. For instance, participants reported difficulties paying. One participant complained that she did not have a table to sign the credit card. Another participant explained that she could not hide her pin number when paying because she was not able to use the counter. Accordingly, participants had to go to the other side of the counter or to another room to interact with the staff or the staff came to other side of the counter and helped them pay or sign the papers.

5.3.7. Challenge 7: Circulating in the examination room and X-ray cabins

In addition to the spaces described in previous sections, participants complained about the small space of the dental examination room. Although most of the dental clinics visited by the participants had several examination rooms, the majority of them were small and did not fulfill the participants' needs. Some participants mentioned that when they were looking for a professional, several dentists had very small examination rooms; they thus had to continue searching for an accessible clinic:

> *I really shopped around and most places that I was going to were not accessible, either they had stairs and if they had no stairs, the rooms were not big enough and they could not work in my chair, so to do a transfer was major. [Int.13]*

The participants complained that they were not able to circulate adequately. Even when they could enter the room, they lacked space to move around. For example, a participant said that the staff had to arrange the office furniture (e.g., removing the dental stools and some machines out of the room) to let her enter the room and transfer to the dental chair. Then, the staff had to move the wheelchair out of the room and bring the equipment back in. The small space of the clinic was one of the reasons (after the high costs) for which this participant decided to change her dentist:

> *[It is not easy to maneuver] to go in and you know try to get in the space because they have to take out the chair, take out the... not the chair but the chair of the dentist and everything and often there are extra machine, they have to push that out. So I can, you know, go backwards so I can transfer. [Int.2]*

The small sized rooms also caused other challenges to the participants. For example, it was hard to drive the wheelchair, especially the electric wheelchair, in such a small space. One participant recalled that during her first visit to the clinic she hit the walls when driving her wheelchair and the clinic had to repair the walls. She said that it took time for her to get used to controlling her wheelchair in the small space of the clinic. Another participant stated that she felt uncomfortable in small rooms. She was afraid to break something or she felt unwelcome. In another case, the participant's assistant [1] carried him in his arms into the

[1] As the participant is not able to talk, it's been for 30 years that he communicates by the help of his friend and assistant. His assistant is completely familiar to participant's conditions. In this interview they answered the questions together; they completed each other's answers.

examination room because the room was very small and he could not enter the room with his big electric wheelchair:

> *It's tight. I'll be honest with you I actually at the beginning I did hit their wall a few time [...] which I felt terrible just because they had to repair the corner that I hit, that's all tight, it's very tight. It's definite that it could be wider; it would be nice if it was wider. [Int.7]*

> *[When the room is small I feel] uncomfortable, because you are afraid of breaking something and you don't feel as welcome.... [Int.4]*

> *[Participant's assistant said that: they should have at least] one large room so that the person can approach with his wheelchair and transfer more easily because we cannot bring his wheelchair in the office and its longer [the distance] for me to carry him. [...] so if we can enter with the wheelchair to the room closer to the dental chair it would be simpler, easier.*

According to participants, the x-ray room is another very tight space that creates a big challenge for them and the professionals. One person mentioned, for instance, that entering the room was difficult because of the narrow door; another explained that it took a long time for her to park her wheelchair in the X-ray room when trying not to scratch the walls:

> *The x-rays... Oh, boy! That takes a long time for me to park and get in, because it's so small the cubical, I mean just enough room for my chair and I have to be very careful not to scratch all the walls when I back up, because it's like perfect for the chair but not enough to drive, it is very small. [Int.7]*

5.3.8. Challenge 8: Being transferred to the dental chair

In this process two factors played important roles; first, the design of the dental chair and second, the skills of the dentist and staff helping the participant to transfer out of the wheelchair.

5.3.8.1. Dental chair

The participants considered that the dental chairs were not designed for the needs of people with physical disabilities. There were two major problems with the dental chair: (i) Transferring from the wheelchair to the dental chair; and (ii) Comfort and security of the dental chair during the treatment session. We will now describe these problems in more detail. In general, the design of the dental chair was, as one participant said, not "transfer friendly". Participants complained that the style of dental chair did not let them move easily in and out of the chair. According to one participant, the dental chair is like a hole that he couldn't get out of. The form of the dental chair made transferring very challenging, especially when returning to the wheelchair:

> *Well, it was not perfect but at least they took the time and they had some people so yeah, it went well but it's easier to go from the chair on than back. Coming back on the wheelchair was more challenging, because it's lower and the position of the feet is that way, it's in angle so all those factors made more difficult to go back on the chair. [Int.6]*

Another problem with the dental chair was the fabric used for the cover. Participants had complaints about the materials. When the cover was made of leather, transferring was more difficult because leather was sticky and the participants couldn't slip easily onto the chair. On the other hand some plastic covers were too slippery and the participants who were not able to keep themselves stable tended to slip while on the chair. For example one participant's assistant had to pull him to a comfortable position once in a while during the treatment session because the cover was very slippery:

> *[His assistant says] La forme de la chaise. Because the chair is narrow, the person has to work on a certain degree, he has to be in a certain inclination also but he slides because of the texture, the texture of the seat is sliding, I know it's easy to clean for the dentist but for people they cannot stay in the same stable position, slides, when you slide it's not very comfortable. He has a body that needs to be stable. Scoliosis needs*

pillows, that's for sure, sometimes I have to pull him so that he's comfortable, his head and here and stabilize him, 3-4 time in 3 quarters of an hour I have to, because either he goes on the sides, either he goes [down]. [Int.11]

Other problems were related to arms, height and shape of the chair. In some old clinics the arms of the chair did not slide; consequently they blocked the participants' way for transferring easily. Some participants complained that because the arms presented a barrier between the chair and wheelchair, they needed someone to lift them and help them pass over the arm.

The height of the chair was also a problem for some participants especially for the persons who had knee problems. For instance, a participant mentioned that even the lowest level of the chair was too high to transfer. Another one mentioned that the chair was either too low or too high and that she always needed someone to help her to go in or out of it.

Another complaint about the dental chair was lack of enough supportive parts (e.g., bars, anchors and hinges) to help with transferring. When transferring from one chair to another, participants indeed needed proper handles; one participant explained that without enough supports on the dental chair, he was helpless and the whole transferring process was performed by others. These bars should have hinges and be adjustable to go up and down easily to suit different conditions and sizes of patients:

On the chair of the dentist you don't have support, you don't have anchors, guiding bars, you know hospital beds they have, on the sides, these hinges that you could easily manipulate them, put them down or up, lift them, so if somebody could transfer to these chairs, they should at least put them these bars and anchors in order to prevent them from falling. [Int.9]

The position and the fact that there is not much place to push on it... no grab you know... but to do a push up to transfer so the way it's made is not easy to transfer. [Int.6]

5.3.8.2. Skills of dentists and their staff

The participants explained that dental professionals played an important role in the process of transferring, especially when it was done by hand and not by mechanical devices. Although the ideal way to transfer was using lifts, none of the participants reported being moved by such appliances in a dental office. All participants who sat in dental chair had done the process themselves or with the help of someone else. The level of the disability indicated necessity of help required and, in our sample, the majority of participants needed help to move from the wheelchair to the dental chair and back. So absence of the lifts in dental offices and limitations of the participants increased the importance of the "help factor" in the process of transferring.

Sometimes dental professionals were not willing to help participants and sometimes they did not have the skills to help them. Consequently, several participants had to ask a family member, friend or their assistant to accompany them to the dental clinic. For example, as mentioned before, one participant explained that, according to her dentist, "If I wanted to stay with her, I had to transfer into that chair", by bringing someone with her to the appointment to help.

Many participants complained that dental professionals were not familiar with techniques of lifting and consequently they were reluctant to help or their help was insufficient. For example, one participant said that transferring was complicated because of her weight. She consequently required 2 strong and skilled people to help her but it was obvious that dental professionals didn't have any training to transfer her properly. Another participant said that he had to stay in his wheelchair during the treatment because his arms were completely paralysed; he could not actively participate in the process of transferring. On the other hand, if others lifted him; they could hurt him or themselves, so they didn't take the risk of lifting him:

They tried [to help] but I had to tell them "no, wait, this is the way that I want you to do it", they knew enough to put the brakes on, you know. [Int.12]

For me because they didn't get the training to properly transfer me and because I can't lift myself at all it's complicated, you have to know what you are doing. [Int.4]

In addition, the dentists and staff usually didn't know how to handle the participant's wheelchairs after the participant sat on the dental chair. For example, a participant said that the staff members couldn't take her electric wheelchair out of the room because they didn't know how to make it work:

[...]And then they have to take out the brakes out of my chair, move the chair because they don't have enough space to move around me to do the work that they have to do, so it's very difficult you know and they try to take the chair out of the space but they can't because they don't know how to… They are not used to work with the chair so it's not easy. It's not easy for them; it's not easy for me. [Int.2]

5.3.9. Challenge 9: Overcoming discomfort during treatment session

5.3.9.1. Comfort in the dental chair

The second group of problems related to dental chairs was security and comfort during the treatment session. One problem was the risk of sores and perspiration during a long treatment session. For example, a participant said that her wheelchair had a special cushion with bubbles that prevented sweating but on the dental chair she felt uncomfortable and sweated a lot.

Another problem was the form of the dental chair, which was not convenient for lengthy sitting. The participants needed cushions and pillows to support their necks and legs; otherwise they would feel severe back pain. For example, one participant said that she was not able to lie down on the chair completely flat so she had to ask the staff to put cushions under her legs. However, sometimes even

the cushions and towels did not prevent the pain. A participant stated that he was not comfortable when he had to lie down on the chair and despite breaks during the treatment and cushions, he felt pain in his neck and shoulders the day after treatment:

> *[pain] maybe not right away but next day, one shoulder or both that hurts just because, even though she put a towel, that helps but it's not... it doesn't give complete support, say my head should be like this, you know when I'm lying down it's like this and there is a small cushion but it is not sufficient enough. [Int.12]*

> *She set me on this chair, adjusted me to get flat completely, I said I cannot do it because of the problem of my back, I have pain so what I was tried to do was to put some cushions underneath my legs my knee in order to not to get back completely so I was like at an angle and this is really torture. [Int.9]*

A third problem related to the comfort of the dental chairs was that the lower portion was not adjustable. Participants, especially the people with arthritis, who were not able to bend their legs, needed the chair to support their legs. For example, a participant said that she was not comfortable to sit on the chair for a long time because one of her legs was hanging a little and the angle of the chair was not right to support her leg:

> *My leg doesn't bend and the chair has always this little (imitates the shape of the dental chair) one leg is a little bit hanging so for longer periods that's always uncomfortable. [Int.5]*

Some participants were afraid of falling from the dental chair because the chair did not have bars on the sides to support them; when their legs had spasms, they felt at risk of falling. To prevent this and increase comfort, participants explained that they brought cushions to the clinic to support them on the dental chair.

5.3.9.2. Transferring or staying in the wheelchair during treatment

Because of the difficulties in transferring and sitting on dental chair for a long time, most participants preferred to stay in their own wheelchair. The dentists and hygienists, however, seemed reluctant and found this solution less desirable. For instance, a participant explained that a hygienist complained because the participant could not transfer to the dental chair:

> *There are not very many of them [that work for you while you are in your wheelchair], actually I found only one. But there is one other, here at Place B, but he doesn't accept welfare insurance. So that's another little barrier. [Int.8]*

> *Because I can't transfer on the dentist chair and she said to me "oh, it's more difficult to take care… on your wheelchair" and I don't like very much the way she told me this thing and I take a decision to go at other place, other dentist, yeah. The hygienist that is the person that is not very kind. [Int.10]*

Participants reported several factors which influenced whether or not to transfer. In this section, first, we will explain the factors that made the participants avoid transferring and then we will describe the factors that obliged the participants to transfer.

The first factor was feeling pain during transferring and sitting in the dental chair; it was an important issue that made participants reluctant to be transferred. A participant said that she was not able to transfer because she had a lot of pain when other people touched her neck and shoulders. Another participant mentioned that some people using a wheelchair did not go to the dentist just because they had to be transferred by hand and transferring is painful for them.

The second factor for avoiding transferring was spasms, which will be discussed in the next sections. The third factor, as a participant stated, was "weak bones".

Some people have a harder time, the pain and as soon as they are not sitting in their own wheelchair it can be very painful. Or some people just can't be transferred because of weak bones, so they can't be transferred by arm or because of pain in the shoulders. So they'll choose not to go to the dentist because they cannot find a dentist that will treat them in their own wheelchair or they don't have the wheelchair that can tilt back. It's not everybody that can have the wheelchair that can tilt back, and when you are in the regular wheelchair, just manual wheelchair, then it's not possible to stay in your wheelchair for the treatment. [Int.4]

The fourth factor that made transferring difficult was the design of the dental chair, which we presented in a previous section and will not describe again.

In addition to the factors above, there were a lot of details during transferring that made the participants uncomfortable:

I have to go in and try to work my way in and then transfer and then place my feet and everything and then I have to transfer back and place my clothe. That's another thing because when I'm going back on the chair, my clothes are not like all [...] right, I have wrinkles and everything and the bottom under me, so I have to try to take out the wrinkles and everything but it's not easy. And my feet are strapped on my chair and I have to re-strap my feet... so it's long... lot of things. [Int.2]

There were important reasons for which transferring from the wheelchair to the dental chair was necessary. For example, the wheelchair was not designed to perform dental treatments. So, even if the dentist accepted to work without transferring to the dental chair, it was sometimes impossible. For example, some wheelchairs did not tilt back or adjust to a comfortable position for the dentist. It should be mentioned that it is not always possible to have a special kind of a wheelchair that can tilt back. As one of the participants explained, it depends on economic and sometimes health conditions:

If I would stay in my chair, that wouldn't be a problem. The thing is if I have… they call it a "bascule" I don't know the word in English. If they have the bascule I lowered my chair and do that as a chair of the dentist,

so they could do the work as I stay in my chair, but I don't have that because I'm not sick enough [to get one of those wheelchairs]. [Int.2]

They [the doctors] wouldn't let me have the back that goes down. They said it would make me slide down the chair; I would not be in right position any more. They only do it for people that can lift themselves up and place themselves back in the right position. [Int.4]

Another reason that necessitated transferring was the small space of the examination rooms. When the examination rooms were very tight, the participants were not able to enter and move in the room; also the dentists and staff did not have enough space to do their work; so the participants were obliged to transfer to the dental chair.

Similar to other phases, progressive conditions of the patients affected their functioning (here, ability to transfer) and made transferring more difficult. For example, some participants used to transfer when their disability was not severe, however, with its progression (e.g., increased pain, reduced balance or more limited movements), they needed help to move to the dental chair or they were obliged to stay in the wheelchair:

Since about 2 years now I had herniated lumbar disc and it's got much worse so I can't get on to the chair of the dentist any more but my electric wheelchair tilts back, you know? But they are not as comfortable, they let me do it, they don't have any choice... they lose the patient, you know? [Int.7]

5.3.9.3. General health related issues

5.3.9.3.1. Urinary catheter with drainage bag

Special health conditions were another major challenge faced by participants during the dental treatment. For example, a participant, who used a catheter with a drainage bag, explained how her position on the dental chair caused distress. As the bag was placed on her leg, when her legs were higher than her body, her

bladder could not empty and she would feel uncomfortable. In these cases she had to ask the dentist to interrupt the work and change her position to let the bladder empty.

For this reason, participants using a catheter explained that they would avoid drinking liquids before going to the dentist, especially 1 or 2 hours before. On the other hand, they felt the need to drink a lot of liquid because the medications they took caused dry mouth:

> *I have a [drainage] bag because I have a catheter... because my bladder is paralyzed…. The thing is when you are on the chair, they put you like your head is lower than your feet so the bag is on my leg, so the thing is the urine which is in my bladder cannot go to the bag because the bag is higher than my leg, so I don't feel good, so I'm starting not to feel good you know, I have like sweats and everything, so I have to stop what they are doing, sit for 5-10 minutes you know just to be sure that my bladder just empty itself and then I can go back. [Int.2]*

> *First I have to check what I am drinking. I cannot be on the chair long. I have to check what I am drinking before going there and I'm taking a lot of medication because I have a lot of pain, that's another thing and because of that my mouth is always dry so I have a tendency to drink more so when I'm at the dentist, it's not easy too because I can't drink before, so I have to check that. [Int.2]*

5.3.9.3.2. Spasms of the legs

Another condition that made participants uncomfortable during the treatment sessions was spasms. While some of the participants did not experience this condition, others with spinal cord injuries and cerebral palsy had muscular contractions of different levels of intensity. The participants stated different reasons for spasms. Most of the time, it happened when the participants were sitting for a long time in one position. Also it happened when they flexed their muscles; in severe cases, any unexpected movement would cause spasms. Some

of the participants consequently took anti-spastic medications before going to the dentist:

> *I would also take one more medication for the spasms. When I had to transfer into the [dental chair] I would take more medication to make sure that I didn't move when they were working, because I have a lot of spasms, especially when I'm not in my wheelchair. [Int.4]*

When the spasm happened in the dental chair the participants needed pauses to wait for it to subside. One participant said that sometimes he was able to prevent them. But when he failed to do so, he had to ask the dentist to stop and move the chair up so that he could deal with the contractions. Another participant explained that spasms started when he changed his position and put his legs in extension. Another one with more severe health conditions had these muscular contractions with any unanticipated actions by people around him and, as his assistant explained, the dentist should be very careful and delicate with him to prevent strong spasms:

> *Then I have to tell them you know, when I know that it's coming I'm not moving and nothing would happen. But there are times when even though I try to not make the spasm happen, it does so I have to tell the dentist if he or she doesn't already know, to change the position of the dental chair bring me up so I can deal with spasms. [Int.12]*
>
> *[His assistant says] He has medication for that. For the strong spasms on special, like if you are surprised, like if the dentist is very "brusque", then he has [spasms] because of the surprise, he needs delicate action. When he is irritated, he needs calm and delicacy and politeness. If you go that way you don't provoke spasms. [Int.11]*

Participants explained that spasms on the dental chair could be dangerous because of the risk of falling. This was particularly important for participants who were less mobile. For example, one person reported that sometimes her legs would start moving and falling from the dental chair. The dentist then would have to stop, put her feet back on the chair, and wait for the spasms to finish:

I have a lot of spasm in my legs so sometimes my legs don't stay still, so they could begin like that… and they can fall from the chair, so they [dentist] have to stop, take off my legs… and that's another thing, if I would stay in my chair that wouldn't be a problem. [Int.2]

5.3.9.3.3. Pain in body

Most participants felt pain in various parts of their body, especially in their back, neck, and shoulders. In some cases the pain was chronic and related to their disability; in other cases the pain started because of an awkward position in the dental chair. Some participants consequently took pain medications whereas others were able to handle it without painkillers:

I get pain but I handle it fine. [Int.4]

I'm trying to lower the morphine a little bit, so there is always pain even with the morphine at the high dose, there is always pain but is not as bad so now that I've had lowered the morphine to third of the dose. [Int.7]

As described before, some participants reported that the pain increased when they transferred to dental chair. They also complained about the pain in their back, neck and shoulders when sitting on the dental chair for a long time because of the uncomfortable position. The staff usually put a towel or cushion under their neck or back to make them more comfortable but sometimes it did not suffice. Also, keeping the mouth open for a long time caused jaw pain in participants with arthritis, who then needed pauses to rest their jaw:

Like I said when I had pain in the jaw and you know I would ask to stop and they went to another patient and come back to me because I could not be too long with the mouth open. So if I had a repair that had to be done, that had to be done gradually. [Int.13]

5.3.9.3.4. Problems in opening and closing the mouth

As previously mentioned, the participants with arthritis and muscular dystrophy had difficulties in opening and closing their mouth. This caused difficulties in maintaining good oral hygiene and problems during the treatment sessions. For example, a participant explained that her limited mouth opening complicated her treatment; she also deplored that the dentist complained about this and considered her as a difficult patient. Another participant, who could not close her mouth completely, had liquid accumulated in the oral cavity which leaked everywhere during her dental treatment:

> *I go for my fillings there and the last 2 that I got were in the back and I cannot open my mouth very wide. And she complained the whole intervention that "oh, if you have another one that's this far I won't be able to do it"; so what I'm gonna do?! [...] she didn't like that my mouth wasn't opening as much. [Int.5]*

> *She made me feel bad about my mouth not opening as wide as the rest of them; of course I'm like enduring a lot of pain because when she says "open!" It hurts so much and already putting up with all of these pains and on the top of that, I don't really feel good […]. [Int.5]*

Consequently, because of these experiences, some participants were afraid of going to a new dentist or to change dentists. For example, the participant whose dentist complained about her limited mouth opening wanted to change dentists but she was afraid that all dentists would be the same:

> *She was complaining a lot. I'm afraid everyone gonna complain if I go to a different dentist. [Int.5]*

On the other hand, in some clinics, dental professionals were sensitive to the limitations of people using a wheelchair and knew what to do. For example, a participant explained that although she was unable to open her mouth wide, her dentist never complained and had done very good work for her back teeth. Participants believed that when the clinics had more than one patient with

disabilities or had gained experience, they were more accustomed to their needs and limitations. In addition, some participants believed that young dentists were more skilled and sensitised about people with physical disabilities:

> *Well... the fact that the association here recommended I guess... they had a sensibilization about this problem and they worked with people with disabilities, but I don't know if there's a lot of people that use their service. [Int.6]*

5.3.10. Challenge 10: Financial barriers

Most participants were not satisfied with their economic conditions. Although a few had paying jobs, the others were unemployed because of their disability and did volunteer work with no salary.

Some of the participants were on welfare although only a few who used to work before their disability received a disability pension.

According to the participants, the costs of dental services were high and, because of that, some of them were unable to undertake all necessary treatments.

There were two groups of participants. One group, who did not have a dental insurance and had to pay all dental costs from the money they received for their living expenses, and another group, who had dental insurance. The participants without insurance were reimbursed a small amount for their medications by the government but they did not receive any reimbursement for their dental care expenses in particular:

> *I get my medication reimbursed and things like that but not the dental care, it has to be something related to disability to be reimbursed. [Int.4]*

For the group of participants who had an insurance, the benefits were not the same for all persons. The coverage rate depended on participants' current and past status of employment or on their ability to buy private dental insurance. However,

it should be mentioned that none of the participants were satisfied with their dental insurance plans.

The participants who had a paying job had dental coverage through their employment. They had to pay monthly fees and a percentage of the costs but they believed that the amount of the coverage was not sufficient. One of the participants complained that her insurance was set at the minimum level because they only paid for a cleaning every 9 months and about 200$ for surgeries:

> *In my company at least I have a minimum dental insurance but dental insurance doesn't cover everything. My company offers me the minimum say example just for cleaning your teeth every 9 months per year, so every 9 months I go clean. Second, they cover a minimum I don't know say 200$ say for operation but you know pretty well that any operation costs more than a 1000$, so it's compared to what you pay. [Int.9]*

Some unemployed participants had or used to have private dental coverage but often they were not satisfied with the costs of the insurance. Some of them had cancelled their insurance because they felt the monthly amount was excessive or because they could not afford it. For instance, a participant who had a dental insurance plan before her accident could not renew it because the fees – 60-70$ per month – became too high for her. Another participant had insurance through his bank but cancelled it to rely on his welfare insurance.

The other group of participants was living on welfare and used the dental coverage provided by the government of Quebec. This kind of dental insurance only covered basic treatments and dental checkups once a year. For other treatments or additional checkups, the participants had to pay the costs out of pocket. For example, one participant explained that he had to pay for a composite filling of a molar because the government only pays composite fillings for front teeth not for the molars. Other participants complained that welfare covers only one cleaning per year; they consequently had to pay the second one themselves:

> *And they stopped using amalgam […], just composite, which is white, and the government doesn't cover that for a molar, they cover that for the front teeth but not for the back teeth. So I was able to get my cavity repaired but then I had to forget the money for the whole payment, the cavity repair so that's another challenge. [Int.8]*
>
> *Once a year, one cleaning is covered, one cleaning and all extractions are covered; all the rest I have to pay. [Int.12]*

The participants had different solutions to reduce their dental service costs. One solution was to choose cheaper treatments, even if these treatments would not solve their dental problems completely. For instance, a participant explained that when his dentist listed the services that he needed, he asked him to do only the cleaning and fillings and not more.

Another solution was changing the dentist and going to a cheaper dental clinic or hospital. Some of the participants chose a middle way: they would consult their regular dentists for some treatments but, for the rest, they would go to a clinic or hospital providing free or cheap dental services:

> *Well, actually, most dentists are pretty good from my experience anyway, [...] they look at your teeth, they say "oh I could do this for you, I could do that for you" and I looked at them all and say I don't have the money for that, I'd like to but… (He laughs), you know, I just need repair or check or my teeth cleaned for annual checkups. [Int.8]*
>
> *Because, well it's a little hard to floss and everything with my hands so I prefer going more but then I wouldn't, like, to pay for both visits so I use the free M clinic as a supplement, yeah. [Int.5]*
>
> *It's very expensive, so if I get my repairs done in the summer, I'll just go for my cleaning in the winter by the dentist. [Int.7]*

Furthermore, the high costs of the dental services forced some participants to reduce the frequency of the dental checkups, pay the fees in instalments, or even borrow money from their family. Most participants would have preferred consulting twice a year but had to reduce the frequency of their dental checkups to

once a year. As for the participants on welfare, they also regretted that their public dental insurance covered only one check-up per year:

> *It's expensive, I try if it wasn't as expensive I would probably go [for checkups] twice a year but because it's so expensive, I go just once a year. [Int.4]*

> *It would be better if I would have access to dental checkups every 6 months because I can't brush my teeth as well as I used to when I was fully able, but my public insurance only allows me once a year so…. [Int.8]*

5.3.11. Challenge 11: Time

Another issue expressed by participants was the length of the sessions at the dental office. Moving in small spaces of dental clinics, entering into the examination room, fitting the wheelchair in the room, transferring into the dental chair and going back to the wheelchair, in addition to pauses because of health issues, were time consuming and thus required longer sessions:

> *Always, always [flexible] and they always figure longer time for me because they figured that I need to transfer in, transfer back, so they always, you know, yeah they are flexible they're very good people. [Int.2]*

> *It takes more time that's why one session with one of the cases will take probably double the time that takes with the regular person, I'm exaggerating but at least 1.5 times the time that usually take the regular cases. [Int.9]*

During the treatment, health related issues called for pauses. The participants with arthritis needed breaks because keeping their mouth open for a long time caused pain. Persons using a catheter with a drainage bag also needed pauses for the reasons outlined earlier. Sometimes, spasms occurred during the treatment and the dentist needed to stop the work and wait for the spasms to finish:

Well with my arthritis, I cannot have my mouth open too long or the pain starts, so he takes a break, I take a break, both take breaks, it's team work! [Int.13]

6. Discussion

6.1. Summary of results

Our study reveals that people with disabilities face many challenges in their dental care pathway, as summarized in Table 4. Within our sample, two principal groups of barriers can be identified: firstly, that of environmental factors and secondly, that of factors related to dental care providers.

Environmental factors mainly relate to the way buildings, dental offices and transportation are organized in addition to complications in treatment sessions and in transferring patients to the dental chair (challenges 1, 3, 4, 5, 7, 8, 9). As our findings illustrate, these environmental factors are not flexible enough to appropriately accommodate a person using a wheelchair.

The second group of barriers is related to dental professionals' behaviours, skills and personnel, which in most cases do not fit the needs of people using wheelchairs, imposing on these patients a difficult search for an informed and accessible dentist (challenges 1, 2, 6, 8, 9).

We can also classify our results according to the 5 areas of access defined by Penchansky (57). Characterized as "the degree of fit between patient and health services" (57) the areas of access include availability, acceptability, accessibility, affordability, and accommodation. These areas are variably found across environmental factors and factors related to health care providers.

It needs to be noted that the 11 challenges mostly fall in the area of accommodation. This illustrates that dental care services exhibit structural deficiencies that lower the quality of care for people with disabilities. All the same, the nuances of these challenges stretch across all five areas of access, and are summarized below:

- **Availability** (environmental and provider-related factors)

Problems in finding an accessible dentist reveal a lack of availability of dental services for people using a wheelchair.

- **Acceptability** (provider related factor)

Recurrent rejection by dentists and inappropriate behaviours on the part of dental staff towards patients using a wheelchair implicates lack of acceptability among dental professionals regarding people with disabilities.

- **Accessibility** (environmental factors)

The accessibility of dental services is compromised for people using a wheelchair because this group faces difficulties in organizing appointments and transportation for their dental visits.

- **Affordability** (environmental factors)

Insufficient insurance plans and the high costs of dental services produce a lack of affordability for people using a wheelchair.

- **Accommodation** (environmental and provider-related factors)

Representing the majority of the challenges that we have identified, accommodation issues refer to the inhospitable design of dental clinics and maladaptive behaviours of the staff. These problems may manifest through difficulties in entering the buildings and moving inside dental clinics. Different spaces such as waiting rooms, hallways, washrooms and examination rooms may all feature significant failures in accommodation. Additional difficulties such as patient transfers from the wheelchair to dental chair indicate that dental professionals may lack skills.

Table 4. List of challenges our participants faced in their dental care pathway

	Challenges faced by people with disabilities	Types of access
Challenge 1	Finding an accessible dentist	Availability
Challenge 2	Being accepted by a dentist	Acceptability
Challenge 3	Organizing the appointment and the transportation	Accessibility
Challenge 4	Entering the building	Accommodation
Challenge 5	Moving inside the clinic	Accommodation
Challenge 6	Interacting with the staff	Acceptability
Challenge 7	Moving in the examination room and X-ray cabins	Accommodation
Challenge 8	Being transferred to dental chair	Accommodation
Challenge 9	Overcoming discomfort during treatment session	Accommodation
Challenge 10	Financial barriers	Affordability
Challenge 11	Time	Accommodation

6.2. Limitations and strengths

6.2.1. Limitations

This study has been conducted in Montreal, Quebec, Canada, and as such our results should not be widely generalized to other social, political and cultural contexts. Nevertheless, some of the challenges that we describe may occur to

varying degrees in other provinces and countries, especially if they share some of the characteristics of the Quebec health care system and its regulations. Our results may thus be transferrable to other contexts, and we invite the readers to assess the differences and similarities between these contexts and to decide to what degree our findings may be transferred.

The small sample of 13 persons may appear to be a limitation by some standards. However, to qualitative researchers, relatively small sample sizes are not uncommon. Our sample size is reflective of a saturation point at which additional participants would not add new significant information. Indeed, as Guest explains, according to the standards of qualitative research, such sample sizes are entirely sufficient "to understand common perceptions and experiences of relatively homogeneous individuals." (131).

6.2.2. Strengths

We adopted a qualitative descriptive approach, which is a pertinent methodology to gain original knowledge about an underexplored subject such as our own.

Our study is built around the principles of participatory research (PR) which means that we engaged people using a wheelchair in the research process, attempting to bridge the gap between knowledge and practice (136). As explained by Cargo and Mercer, "a key strength of PR is the integration of researchers' theoretical and methodological expertise with non-academic participants' real-world knowledge and experiences into a mutually reinforcing partnership"(136). In this case, partnerships were formed among researchers, dental professionals and people using a wheelchair. These partners provided practical solutions to the research problem which can facilitate a quick and responsive translation of our knowledge into action.

A final strength of this project is its lack of specificity regarding diseases or diagnoses in its sample. Instead, there is a fair degree of diversity in the study as

our sample encompasses participants with several kinds of diseases and injuries that have resulted in mobility limitations (137). These included spinal cord injuries resulting from accidents, chronic diseases such as arthritis and developmental disabilities such as cerebral palsy. The primary unifying trait in our sample was simply the use of a wheelchair. Accordingly our findings may apply to a wide range of people.

6.3. Interpretation

To the best of our knowledge, this study represents the first research that voices the experiences of people using a wheelchair with respect to the access of dental services. Some of the challenges that we explored are more largely documented in the medical field by different authors such as Drainoni, Kroll, DeJong, and Iezzoni (11, 13, 94, 138). Their studies describe a range of issues, including structural problems in physical environments, transportation, financial issues, and personal factors. This study describes challenges that are very specific to dentistry. It therefore explores new territory in documenting issues such as problems in transferring to and sitting in dental chairs during treatment sessions. It also provides insights into the specific relevance to oral health of some of the physical conditions of the participants such as limitations in opening their mouths.

Our interpretations are in accord with the social model of disability. As it details, society principally produces social and physical barriers for people with disabilities by creating and maintaining inaccessible environments. Consequently, we believe that it is the responsibility of society to increase the participation of people with different needs by removing social and physical obstacles and accommodating the maximum number of people with a wide range of functionality and ability.

Moreover, as Article 2 of United Nations Convention on the Rights of Persons with Disabilities (ratified by Canada as of March 11, 2010) states, the “denial of

reasonable accommodation" constitutes a form of discrimination. The convention further obligates its signatories to take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise (Article 4). This legislation mandates States to provide the same range, quality and standard of free or affordable health care and programs to persons with disabilities as to other persons (Article 25). We believe that in the field of dental services, people using wheelchairs face discrimination as they are not afforded reasonable accommodations. The government has the responsibility to eliminate discrimination by removing the barriers in their dental care pathway, thereby providing affordable, accessible and high quality dental care for all.

6.4. Recommendations

Our study illustrates that people using wheelchairs face discrimination in accessing dental services. As these barriers are socially constructed, it is appropriate to call upon society to remove them. As evidenced in our findings, several sections of society have important roles in training dental professionals, providing dental services and assessing the quality of the services given to people with disabilities. Our recommendations are summarized in Table 4, and are addressed to the following five sectors: the government; dental schools and dental educators; Order of Dentists of Quebec; dentists and ACDQ (Association des Chirurgiens Dentistes du Québec); and organizations supporting people with disabilities.

6.4.1. Government

The Canadian government, by ratifying the UN convention on the Rights of Persons with Disabilities, has committed to eliminate any type of discrimination against people with disabilities. Moreover, the national Charter of Human Rights and Freedoms (passed by the National Assembly of Quebec on June 27) states:

> *Every person has a right to full and equal recognition and exercise of his human rights and freedoms, without distinction, exclusion or preference based on race, colour, sex, pregnancy, sexual orientation, civil status, age except as provided by law, religion, political convictions, language, ethnic or national origin, social condition, a handicap or the use of any means to palliate a handicap. Discrimination exists where such a distinction, exclusion or preference has the effect of nullifying or impairing such right.*

Following from these legal principles, both the governments of Quebec and Canada have the responsibility to oppose discrimination leveled against people with disabilities. In order to adequately fulfil this obligation, we recommend that:

1. As denying treatment to a person with disability on the basis of their impairment is a type of discrimination, the government has the duty to inform its population about these policies and enforce them. The government should therefore require dental schools and the ODQ to consider the rights of the entire population including those with specific needs in their policies and training programs.

2. Further to this point, the government should also take steps to inform people with disabilities about their rights to dental services as there is not a comprehensive awareness of these legal protections.

3. Additionally, in order to reduce the problems concerning transportation and dental appointments, the government should make further efforts to improve the quality of adapted transport services.

4. Moreover, the government should consider establishing and supporting mobile dental clinics as an alternative or a complement to fixed clinics, thereby providing accessible dental services for people with disabilities as well as for other disadvantaged groups such as homeless people and senior citizens.

5. Finally, in order to reduce the financial barriers to dental care, the government should subsidize the costs of dental services and provide support for more flexible dental insurance plans for people with disabilities.

6.4.2. Dental Schools and Dental Educators

Dental schools are the first place that future dental professionals come to learn their responsibilities regarding society. As such, students are ideally suited to receive training about the special needs of patients with different characteristics and different levels of ability. Our recommendations to dental schools and dental educators are as follows:

1. Dental educators should provide designated hours of didactic and clinical training in their courses for undergraduate dental students, detailing the needs and accommodations of people with a wide range of disabilities.

2. Dental faculties should establish specialist and postgraduate programs on special care dentistry similar to the 3-year Special Care Dentistry (SCD), specialty offered in the UK Royal College of Surgeons of England [2] and King's College London.

3. Dental researchers should conduct studies in partnership with community organizations, ODQ representatives and dentists to answer the following questions:

    i. What kinds of problems and resource limitations do dentists face in treating a patient with a disability?

[2] http://www.rcseng.ac.uk/fds/publications-clinical-guidelines/docs/scd

ii. How can guidelines best be designed through collaboration with ODQ to describe a standard accessible dental office and define different levels of accessibility in dental clinics?

iii. What recommendations could be offered by dentists who have experience treating people with disabilities to improve the oral health and the quality of dental services offered to these populations?

6.4.3. Order of Dentists of Quebec (ODQ)

The ODQ could play a major role in addressing these issues. It has the power to make policies and oblige its dentists to apply them within their own practices. Additionally, the ODQ is responsible for evaluating dental clinics and provide continuing education for dental professionals. Accordingly, we recommend:

1. As physical accessibility is a major issue in the dental care pathways of our participants, we recommend that the ODQ collaborate with researchers to design a guideline for its members. This guideline could further be employed by ODQ inspectors and dentists to assess the accessibility of dental offices.

2. The ODQ should define different levels of accessibility for dental clinics and require this information to be presented in the standard contact information of dentists.

3. The inspectors of the ODQ should regularly evaluate and assess the accessibility of dental clinics.

4. Additionally, the ODQ should implement rules to oblige its members to ensure that future dental offices accord with high standards of accessibility.

5. To facilitate finding an accessible dentist, the ODQ should provide an updated list of accessible dentists and make this list easily obtainable to individuals and organizations supporting people with disabilities.

6. The ODQ should consider a policy for the equal distribution of accessible dentists throughout different parts of the city.

7. The ODQ should include the followings in its continuing education programs:

    - Encouragement for dentists to increase their awareness about people with disabilities in order to improve the accessibility of their current clinics and the rate at which they accept them.

    - The means to increase the skills and knowledge of dental professionals regarding the special needs of people with disabilities.

8. Finally, the ODQ should collaborate with the government to:

    - Apply antidiscrimination policies and advise dentists as to the rights of people with disabilities.

    - Foster positive interactions between dentists and patients with disabilities.

    - Support and establish mobile dental clinics with the aim of addressing the problem of accessibility for several disadvantaged and vulnerable groups of society.

6.4.4. Dentists and the Association des Chirurgiens Dentistes du Québec (ACDQ)

As dentists are the only party that works directly in contact with patients with disabilities, they are ultimately the ones responsible for providing an accessible dental care environment. In order to meet these standards, we recommend:

1. Dentists should respect the rights of people with disabilities by considering the issue of accessibility in the design and management of their clinics and in the acceptance of new patients.

2. Dentists should further train their staff to interact appropriately with different types of patients, especially patients with disabilities.

6.4.5. Organizations Supporting People with Disabilities

Organizations supporting people with disabilities (e.g., RAPLIQ) have a mission to defend the rights of this group. They are their voice, and as such, must report deficiencies existing in different sections of society. Regarding dental services, we recommend that:

1. These organizations should continue their fight against the problems concerning public transportation. This could be furthered by explicitly relating the quality of adapted transport to the problems faced by people using a wheelchair in making dental appointments.

2. They should take efforts to inform people with disabilities about their rights to have an accessible dentist.

3. They should collaborate with the ODQ to provide a list of accessible dentists and make this list accessible to their constituents.

Table 5. Our Recommendations

Challenges Faced by People with Disabilities	Recommendations to Improve Access	Target of the recommendations
Challenge 1: Finding an accessible dentist	1. Rating dentists' levels of accessibility based on the challenges presented in this research. 2. Providing people with physical disabilities with a list of dentists according to their level of accessibility. 3. Increasing the number and distribution of accessible dentists which would include: 3.1 implementing rules to force dentists to make future offices accessible to people with disabilities. 3.2 encouraging dentists to improve the accessibility of their current clinics. 3.3 increasing dentists' sensitivity to the situation of people with physical disabilities.	1. ODQ, RAPLIQ 2. ODQ, Dentists, Dental Educators 3.ODQ, Dentists, Government
Challenge 2: Being accepted by a dentist	1. Increasing the awareness about the dental needs of people with physical disabilities on the part of dental professionals. 2. Advising dentists on the legal consequences of discrimination against people with disabilities, their human rights, and their legal right to be accepted as patients. 3. Issuing sanctions and legal action against dentists who violate these standards. 4. Informing people with disabilities about their rights to have a dentist.	1. ODQ, Dental Educators 2. Government, ODQ 3. Government, ODQ 4. Government, RAPLIQ, ODQ

Challenge 3: Organizing the appointment and the transportation	1. Improving adapted transport services to provide more flexible services. 2. Developing and supporting mobile dental clinics.	1. Government, RAPLIQ 2. Dentists, ODQ, ACDQ, Government
Challenge 4: Entering the building	1. Providing guidelines for dentists to assess the accessibility of their current offices. 2. Requiring dentists to make new offices accessible.	1. ODQ, Researchers, Dental Educators 2. ODQ, Government
Challenge 5: Moving inside the clinic	1. Providing guidelines for dentists to assess accessibility of their current offices. 2. Requiring dentists to make new offices accessible.	1. ODQ, Researchers, Dental Educators 2. ODQ, Government
Challenge 6: Interacting with the staff	1. Training dentists and dental personnel about the rights of people with disabilities and discrimination issues. 2. Increasing dentists' sensitivity to the situation of people with physical disabilities.	1. Dental Educators, ODQ 2. Dental Educators, ODQ
Challenge 7: Moving in the examination room and X-ray cabins	1. Providing guidelines for dentists to assess accessibility of their current offices. 2. Requiring dentists to make new offices accessible.	1. ODQ, Researchers, Dental Educators 2. ODQ, Government

Challenge 8: Being transferred to dental chair	1. Training dental professionals to safely accommodate and monitor the impairment and health of people with disabilities while in transferring. This may, for example, be resolved by installing lifts. 2. Encouraging dentists to provide dental services to patients in their own wheelchair by: 2.1 Discussing the possibility and examining the limitations of their chair. 2.2 Making hoses long enough to be used on a patient sitting in their wheelchair.	1. ODQ, Dental Educators 2. Dentists, Dental Educators
Challenge 9: Overcoming discomfort during treatment session	1. Increasing the skills and knowledge of dental professionals concerning the conditions of people with disabilities.	1. Dental educators, ODQ, Dentists
Challenge 10: Financial barriers	1. Helping subsidise the costs of dental services through government assistance. 2. Providing more flexible dental insurance plans to people with disabilities, covering more dental treatments.	1. Government 2. Government
Challenge 11: Time	1. Encouraging dentists by compensating them for the extra time incurred.	1. Government

7. Conclusion

This study set out to understand why people using a wheelchair experience more dental problems and use dental services less than people without disabilities. Although the literature on the subject confirms that this group has on-going difficulties in accessing dental services, a comprehensive and detailed explanation of the existing obstacles has been lacking. We addressed this crucial omission by studying the origins of this problem and by coming to understand the experiences of people using a wheelchair when contacting dental clinics. Two questions drive this research:

1. What kinds of difficulties are faced by people using a wheelchair in accessing dental services?
2. What potential solutions would facilitate their access to quality dental care?

Overall, our achievements in this study fall into three main categories: firstly, recognizing important issues about the oral health of people using a wheelchair; secondly; describing the challenges that this group faces in their dental care pathways; and thirdly, providing comprehensive recommendations to eliminate these barriers.

Issues

Our study revealed two important issues about the oral health of people using a wheelchair. First, oral health is of a heightened importance to this group, as they tend to use their mouths more than the rest of the population, often referring to their mouth as a third hand. Secondly, largely due to deteriorating health conditions, this population experiences decreasing levels of mobility. Consequently, regular maintenance of individual oral health becomes more difficult and infrequent, eventually causing a marked decline in their oral health.

Challenges

This study suggests that the field of dentistry is not well-organized to fulfil the needs of people using a wheelchair and as a consequence, this group faces discrimination in their dental care pathway. The deficiencies of the dental care system in accommodating this growing part of population are felt in several fronts, including inaccessible buildings, negative attitudes and lack of knowledge on the part of dental professionals and their staff, high costs of dental services and insufficient insurance plans. All these factors complicate the process of dental treatment for this group, and intersect with one another to create a hostile environment for people using wheelchairs.

Importantly, the consequences of this inequity are not limited to their initial effects; the lower use of dental services not only deteriorates the oral health of people using a wheelchair, but also causes more negative effects in the social lives, communication and employment of this group compared to the rest of the population. These facts confirm the importance of this problem and the need for action from a wide range of parties, including the government, dental Orders, educators, researchers and dentists themselves.

Our recommendations

We urge the government, the dental profession, dental schools and groups representing people with physical disabilities to work together in order to improve access to dental services. We hope that the recommendations we provide will be heeded, leading to concrete actions in a near future.

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Appendix A. Consent Form (En)

Consent Form

Title of study: How people with physical disability access dental services?

Principal investigator: Dr. Christophe Bedos; Dr. Belinda Nicolau; Student: Farnaz Rashid-Kandvani – Faculty of Dentistry, McGill University, Division of Oral Health and Society

Purpose of this research study: The purpose of the study is to better understand how people with physical disabilities deal with dental problems and what kind of difficulties they encounter when they need to consult a dentist.

Nature of your participation: We invite you to attend an individual interview as a discussion with one of our researchers. This interview should last no more than 1 h 30. If you find that this period is too long, we will propose to shorten the interview and further discussion for another day, depending on your convenience. The discussion will be recorded with an audio recorder because it is impossible for any researcher noting during the interview. The discussion contained in the audio recorder will then be typed, and then the audio file will be destroyed.

Right of refusal to participate and withdrawal: You have the right at any time to withdraw from the study. If some questions make you uncomfortable, you'll also have the right not to respond. In all cases, you will not face any loss of benefit -which you are otherwise entitled to- because of your withdrawal or because you did not answer.

Confidentiality: Your identity will remain completely confidential: records containing your name and telephone number will be destroyed after the interviews, audio records and questionnaires will be destroyed when their content will be typed. The transcripts of the interviews will not contain any names, whether yours or the name of people you could mention in the discussion. In short, it will be impossible to identify you from the documents released.

Possible risks or benefits: Participating in this interview will not pose any particular risk because it is simply to talk with a researcher and, moreover, we guarantee the highest confidentiality. On contrary, we believe that this study could have positive impacts for physically disabled people in Quebec in terms of access to dental care and oral health in general. Also your participation could have positive implications for the dental profession, particularly through training of university students who will benefit from your experiences.

AUTHORIZATION

I, _____, agree to participate in this study with the conditions described above. I volunteer to participate in this research study. I have read the information on this form and certify that you have answered all my questions and I was given enough time to make a decision. I am free to withdraw at any time without hurting the relationship with stakeholders and without prejudice of any kind. Finally, I was informed that my name will not appear on any public document. I will be given a copy of this form.

Date: …… Signature of participant: .....

Signature of researcher: .....

Contact Information of the Research Team

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Appendix B. Consent Form (Fr)

Formulaire de Consentement

Titre de l'étude: Accès des personnes à mobilité réduite aux services de soins dentaires

Nom du chercheur principal: Dr Christophe Bedos; Dr. Belinda Nicolau; étudiante: Farnaz Rashid-Kandvani Faculté de médecine dentaire, Université McGill.

But de cette étude
Le but de cette étude est de mieux comprendre comment les personnes à mobilité réduite font face à des problèmes dentaires et quel type de difficultés ils rencontrent quand ils ont besoin de consulter un dentiste.

Nature de votre participation
Nous vous invitons à participer à une entrevue individuelle, sous forme de discussion, avec un de nos chercheurs. Cette entrevue ne devrait pas durer plus de 1 h 30. Si vous trouvez que cette période est trop longue, nous vous proposerons de raccourcir l'entrevue et de poursuivre la discussion un autre jour, en fonction de vos convenances. La discussion sera enregistrée car il est impossible pour le chercheur de tout noter pendant l'entretien. La discussion enregistrée sera ensuite dactylographiée, puis sera détruite.

Ethique de la recherche
Vous aurez le droit, à tout moment, de vous retirer de l'étude. Si certaines questions vous mettent mal à l'aise, vous aurez également le droit de ne pas y répondre. Dans tous les cas, vous ne subirez aucun préjudice du fait de votre retrait ou parce que vous n'avez pas répondu.

Confidentialité
Votre identité demeurera totalement confidentielle: les fiches contenant votre nom et vos coordonnées téléphoniques seront détruites après les entrevues; les cassettes audio et les questionnaires seront également détruits lorsque leur contenu aura été dactylographié. Les retranscriptions des entrevues ne contiendront aucun nom, ni le votre, ni celui des personnes que vous pourriez mentionner pendant la discussion. En bref, il sera impossible de vous identifier à partir des documents rendus publics.

Risques et bénéfices
Participer à cette entrevue ne vous fera courir aucun risque particulier puisqu'il s'agit simplement de discuter avec un chercheur et qu'en outre, nous vous garantissons la plus stricte confidentialité. Bien au contraire, votre participation pourrait avoir des répercussions positives pour la profession dentaire, notamment à travers la formation universitaire des étudiants qui bénéficieront de vos

expériences. Nous pensons aussi que cette étude pourrait avoir des répercussions positives pour les populations défavorisées du Québec sur le plan de l'accès aux soins et de la santé buccodentaire en général.

AUTHORIZATION

Je, soussigné(e) _____, accepte de participer à l'étude aux conditions décrites ci-dessus. Je reconnais que ma participation à ce projet est tout à fait volontaire et que je suis libre d'y participer. J'ai pris connaissance des informations inscrites sur ce formulaire et je certifie que l'on a répondu à toutes mes questions et que l'on m'a laissé le temps voulu pour prendre une décision. Je reconnais être libre de me retirer en tout temps sans que cela nuise aux relations avec les intervenants et sans préjudice d'aucune sorte. Enfin, j'ai été informé du fait que mon nom n'apparaîtra sur aucun document public.

Date: …… Signature du participant: .....

Signature du chercheur: .....

Coordonnées de l'équipe de recherche

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Appendix C. Interview Guide

When was the last time that you have had a dental problem? What was the problem? What made you decide to consult a dentist?

1. How was your first visit with the dentist? Could you describe the visit?
2. The whole process in detail: appointment making, transportation, at what time did you leave home to get the transportation? When did the transportation arrive in front of your front door? When did you arrive in dental office? (What time was your appointment?) How did you enter the building...?
3. How many sessions? Did you complete the treatment?
4. What did they do for you?

Finding a dentist / Making an appointment and transportation

1. How did you find the dentist? Did you know a dentist? Did you have a source to get information about a dentist? Friends, organizations….
2. Did s/he accept to work for you? Is there any dentist who did not accept to work for you? How did you feel?
3. What kind of transportation did/do you use to go to the dental clinic? If you "walk", how are the sidewalks?
4. Did you have any problems in making appointment and transportation, being on time?

Accessibility of the building and dental office

1. Accessibility of the building and dental office...
2. Waiting room / Counter / Doors / Washrooms / Stairs...
3. Do you transfer to dental chair or stay in your chair?
    a. **If transfer:** How do you transfer? Does anybody help you? Are you able to take someone to dentist to help you? Who? Why? Did anyone refused to lift you?

b. **If stay on wheelchair:** why? Is the dentist comfortable to work on wheelchair?

4. How was the dental chair? Is it comfortable to transfer?

Individual oral health

1. In a more general way, how often and in which circumstances do you consult dentists? / do you regularly visit a dentist? Dental check-ups? / how important is oral health for you?
2. Individual oral care / physical limitations to brush…. (How about electric tooth brush?)
3. Can you use your hands to floss and brushing? Do you use electric brush? Is there a difference?
4. Are you satisfied with your situation with respect to dental care?
5. Has your oral hygiene changed since you use wheelchair?
6. Do you use your mouth to do things?
7. Did it make problems for you?

General health problems

1. Do you take medications? Do you think they affect your teeth?
2. Do you have dry mouth? Do you use something for that?
3. Do you use catheter? Do you use washroom in dental office? Is it adapted?
4. Do you have pain in your body? Do you use painkillers?
5. Do you sweat or do you have sores after treatment sessions?
6. Do you have spasm in your muscles? What causes spasm? Did it ever happen on dental chair? What did you do then?
7. Do you think that your treatment time take more than normal?
8. Does the dentist sometimes have to give pauses during treatment session?

Economic issues

1. Do you have Dental Insurance? Since when? Which services are covered?
2. What are your financial resources? On welfare, how much the government pay?
3. Do you have any expenses related to your conditions?

Ideal situation/Recommendations

1. How was your relationship with your dentist? Were you comfortable with her/him? Do they behave differently? (Paternalist?)
2. Which of your dentists was the best?
3. What was the difference between this experience and your other experiences?
4. What would be an ideal dentist for you?
5. If you have a dentist, why do you go to this one and what makes you go back to this one?
6. How you compare dentists and dental care to physicians and medical care?
7. Do you have particular recommendations to improve access to dental care for people with physical disabilities?
8. In your opinion, what problems (related to dentist) are because of using a wheelchair?
9. How you summarize your past experiences, what was the main problem that you had? Which ones were more remarkable?

Appendix D. Socio-demographic Questionnaire

Interview No.	
Date:	Time: Place:
1	Gender: Male Female
2	Age: In what year were you born? ____
3	Marital Status: What is your marital status? Do you have children? o Married o Widowed, Divorced, Separated o Never married o Do you live with a partner or family member? (Notes)……
4	Highest Level Of Education: What is the highest degree or level of school you have completed? (Notes)…….
5	Employment Status: Are you currently employed? If yes: what is your job-if no……. o Employed, Self-employed o Out of work o A homemaker o A student o Retired o Unable to work (Notes)…….
6	Do you have dental insurance? What are your financial resources? Welfare?
7	Where Do You Live And The Region? Is this house, apartment? o Owned by you or someone in this household o Rented In which region (city)?

8	Language Of Origin o English o French o Other. Which language?
9	Since when do you use wheelchair? • Since you were born? • Following an accident? Following an illness?
10	Do you use electric or manual wheelchair?
11	Can you walk without wheelchair? How?
12	Do you have a question? Are you interested in the results of this project?
13	Would you mind if I call you in a couple of weeks to ask some short questions?