Access to oral health care for persons who are d/Deaf in Montreal: A focused ethnography

Fahad Ata Siddiqui, B.D.S

Division of Oral Health & Society, Faculty of Dentistry,
McGill University,

Montreal, Quebec, Canada

April 2016

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

“The only true wisdom is in knowing you know nothing.” – Socrates

DEDICATION

To my parents, Mr. Ataullah M. Haqique and Mrs. Azra Khatoon, who always believed in me, and supported me whole-heartedly to pursue my dreams, and instilled in me the important values of hard-work, dedication and honesty

To my loving wife, Dr. Falak Siddiqui, for her untiring support, encouragement, and belief in me

and

To my brothers, Mr. Faisal Siddiqui and Mr. Adeel Siddiqui, for their endless efforts, advice, and selfless support in helping me achieve excellence

ACKNOWLEDGMENTS

First and foremost, I would like to extend my deepest gratitude to my supervisors, Drs. Christophe Bedos and Mary Ellen Macdonald for providing me with a wonderful opportunity to work on a dream research project. I am sincerely grateful to receive the untiring support, wise advice, and hard work of both my supervisors. I feel it has helped me develop the important skills of critical thinking, and empathy, which will help me both as a clinician and a scientist in the future. Thank you for giving me the academic freedom, and trusting me to explore new fronts, and gracefully guiding me along the way to reach my goals. I owe my sincerest appreciation to you both for helping me realize my dream, and positively contributing towards both my personal and professional growth.

A special thanks to the members of the advisory committee of this project, without the collaboration and efforts of whom this study was not possible. I would specially like to thank Dr. Jennifer Paige MacDougall (Canadian Deafness Research and Training Institute), and Ms. Aselin Weng (Seeing Voices Montreal), who provided me with selfless support, and went an extra mile to help me at every stage of this project. I was especially fortunate to have the guidance of Dr. MacDougall, whose expertise in the field of Deaf studies and sign language proved pivotal for this study. I am also very grateful to Dr. Walter Wittich, Mr. Jonathan Jarry, and Ms. Ashanta Farrington of MAB-Mackay Rehabilitation Centre. Thank you for your remarkable support with the participants' recruitment, providing space for interviews, as well as inspiring me to learn American Sign Language.

I would also like to thank the professors, staff, and colleagues at the Division of Oral Health & Society. I highly appreciate the thought-provoking discussions that we have had together at the OHS forums, and to receive your continuous support both academically, and morally. I feel truly fortunate to have known, and worked with such great minds, and above all, even better human beings! A special thanks to Dr. Richard Hovey, who not only offered his kind support and wise advice when I needed them the most, but also through his intriguing philosophical discussions helped me to enrich and broaden my perspectives on life. I am also thankful to Dr. Alissa Levine for her help with French abstract, and for her support and encouragement. A sincere thanks to all the staff at McGill University, especially Ms. Maria Palumbo, who always wore a smile, and supported me generously throughout my graduate studies. I would go to her for any question that

popped up in my head, and she would patiently and gracefully provide me with the 'best-possible' solutions.

A very special thanks to all the members of the Macdonald Lab, especially to Mark Keboa, Crystal Noronha, Nora Makansi, and Shawn-Renee Hordyk, for their genuine concern and support throughout my studies. They truly acted as my elder siblings, kept a check on me, helped me keep sane when things got tough, and constantly pushed me to complete this endeavour.

Being thousands of miles away from home, I feel fortunate to have found friends who supported me, and turned my time in Montreal into a beautiful memory which I will cherish forever. I owe my special gratitude to Ahad Ahmed and Mohamed Nur Abdallah, who supported me throughout, kept me positive, and pushed me to achieve my goals. A special thanks to Sadaf Farookhi for being an active listener, as well as helping me as a research assistant during the data collection phase of this project. Also, I would like to thank Vivek Verma for his thoughtful advice, constant feedback, and reality-checks during thesis writing. Moreover, I am very thankful to Sreenath Madathil, Akanksha Srivastava, Nida Amir, Fahd Ahmed, Basem Danish, and Shadaid Alanezi to have been there for me throughout my journey at McGill.

I would also like to extend my sincerest gratitude to PRAXCIT-CREMIS, McGill Institute of Health & Social Policy (IHSP), Fondation de l'Ordre des dentistes du Quebec (FODQ), Le Réseau de recherche en santé buccodentaire et osseuse (RSBO), Faculty of Dentistry, McGill University, and the Network of Canadian Oral Health & Research (NCOHR) for their financial support.

Lastly, yet most importantly, words are not enough to thank the most wonderful family that I am blessed with. I am most grateful to my parents, who dedicated their lives for the education, and well-being of their children. They compromised their own dreams for fulfilling mine, and taught me to work hard, and to never give up. I cannot imagine achieving whatever I have without their invaluable support. Mummy, Papa, I will never be able to thank you enough! I am fortunate to have a wonderful wife, Falak, whose unconditional love, positive feedback, and support brings out the best in me. She also worked diligently as a research assistant during the analysis phase of this study. I am thankful to have the most amazing elder brothers I could wish for, who have provided me with untiring support, wise advice, inspiration, and motivation in every aspect of my life.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

Background: Over five percent (N=1,266,120) of the Canadian population is reported to have some degree of hearing loss, of which 83,160 persons are profoundly deaf. Persons who are deaf are reported to have both poorer oral health, and oral health knowledge compared to their hearing counterparts in the population. Studies have indicated that due to communication barriers, accessing oral health care services can be a challenge for the d/Deaf community. There is, however, little research regarding the barriers that d/Deaf persons may encounter on their pathways to oral health care. Therefore, the present study was designed to explore the barriers and facilitators of access to oral health care for d/Deaf persons, particularly the Anglophone d/Deaf population in Montreal.

Methodology: Using a participatory research framework, I conducted a focused ethnography to explore the experiences and perceptions of the Anglophone d/Deaf population in Montreal related to access to oral health care. Data collection constituted participant observation at social and educational activities (~50 hours), and 11 semi-structured interviews with d/Deaf participants. All interviews were conducted in American Sign Language (ASL), interpreted in English, and transcribed verbatim. Data analysis included three levels of analysis: 1) within-case; 2) across-case; and 3) ethnographic analysis. Critical theory of disability, and selected components of Grembowski and colleagues' 'public health model of dental care process' guided data collection, analysis and interpretation.

Results: The findings of this study reveal important gaps between the oral health care system and the needs of persons who are d/Deaf. As a result, the Anglophone d/Deaf population face several barriers on their pathways to oral health care, including the following: poor access to ASL interpreters for dental appointments; difficulties in interacting with dental office staff, including telephone communication and in waiting areas; and communication barriers with dentists both during consultation and procedures, resulting from the lack of awareness by dental professionals. Participants proposed several recommendations for overcoming these challenges, starting with health insurance to cover the cost of interpreters for dental appointments; office staff using Video Relay Services (VRS), text (SMS) or e-mail for booking appointments, and dentists asking patients for their preferred mode of communication, removing masks when speaking, and using gestures during procedures.

Conclusion: The d/Deaf population is vulnerable to poor access to oral health care. Barriers that the Anglophone d/Deaf community in Montreal face on their oral health care pathways mainly result from a non-accommodating environment as well as the lack of awareness by dental professionals towards providing care to persons who are d/Deaf. Therefore, the Quebec government, dental educators, and community organizations supporting d/Deaf persons should take collaborative actions to improve access to oral health care for d/Deaf persons.

RÉSUMÉ

Historique: Plus de cinq pourcent (N=1,266,120) de la population canadienne connaît un déficit auditif, et parmi celle-ci 83,160 personnes atteintes de surdité profonde. Chez les personnes sourdes on rapporte une moins bonne santé orale et moins de connaissances au sujet de la santé orale en comparaison avec les personnes sans déficit auditif. Des études démontrent que des difficultés de communication posent un défi à l'accès aux services de santé buccodentaire pour la communauté des personnes sourdes.

Méthodologie: En me servant d'un cadre de recherche participative, j'ai réalisé une ethnographie focalisée afin d'étudier les expériences et perceptions de la population anglophone sourde de Montréal concernant l'accès aux soins buccodentaires. La collecte de données consistait en de l'observation participative lors d'activités sociales et éducatives (environ 50 heures) ainsi que de 11 entrevues semi-structurées avec des participants sourds. Toutes les entrevues se sont déroulées en langue des signes américaine, ont été interprétées en anglais et transcrites verbatim. L'analyse de données inclut trois niveaux: 1) l'analyse du cas; 2) l'analyse de cas multiples; et 3) de l'analyse éthnographique. La théorie critique du handicap ou de l'incapacité, et des éléments du modèle de la santé dentaire publique de Grembowski et collègues ont informé la collecte de données, d'analyse et d'interprétation.

Résultats: Les résultats de cette étude démontrent d'importantes carences dans le système de santé buccodentaire, qui ne répond pas aux besoins des personnes sourdes. Par conséquent, la population anglophone sourde fait face à de multiples barrières: difficultés d'accès aux interprètes ASL pour leurs rendez-vous dentaires; des difficultés d'interaction avec le personnel du bureau dentaire incluant la communication téléphonique et en salle d'attente; des barrières de communication avec les dentistes lors de la consultation et des traitements que les participants attribuent à un manque de sensibilité des professionnels dentaires. Les participants ont proposé diverses solutions pour surmonter ces obstacles, en commençant par la couverture du travail d'interprète par l'assurance dentaire, la communication avec le personnel du bureau dentaire par les services de relai vidéo, textos (SMS) ou courriel pour la prise de rendez-vous. Les dentistes devraient s'informer sur le mode de communication préféré de leurs patients. Ils devraient en plus enlever leurs masques lorsqu'ils parlent et se servir de gestes communicatifs durant les traitements.

Conclusion: La population sourde est sujette à un accès restreint aux soins buccodentaires. Les barrières auxquelles font face la communauté anglophone sourde à Montréal dans leurs trajectoires de santé buccodentaires résultent d'une atmosphère non-accommodante aussi bien que d'un certain manque de sensibilité des professionnels dentaires quant à la provision de services dentaires aux personnes sourdes. Il faudrait donc un effort collaboratif de la part du gouvernement québécois, des éducateurs dentaires et des organismes communautaires qui soutiennent la communauté sourde afin d'améliorer son accès aux services buccodentaires.

Chapter 1: Introduction

According to Statistics Canada (2006a), approximately 1.3 million persons in Canada have some degree of hearing limitation, out of which, almost 83,000 are profoundly deaf (Statistics Canada, 2006a). In medical terms, a person who has a profound hearing loss is referred to as deaf (WHO, 2015). In line with this medical perspective, health care researchers have extensively studied several ways to restore the hearing function in deaf persons (e.g., cochlear implants, hearing aids) (Brown & Balkany, 2007; Niparko & Blankenhorn, 2003; Svirsky, Robbins, Kirk, Pisoni, & Miyamoto, 2000; Yoon, 2011). However, these medical interventions are not compatible with the needs of many deaf persons, particularly those who view deafness as a culture, rather than a disability (Andrews, Leigh, & Weiner, 2004). Opponents of the medical model of deafness believe that, through the use of sign language and unique cultural practices ('Deaf theatre') (Andrews et al., 2004), deaf persons represent a cultural group, which has been coined, the 'Deaf culture' (Reagan, 1995). Persons who identify themselves with the Deaf culture are distinguished with an upper case letter 'D', while the lower case 'd' is used to refer to the audiological condition of not hearing (Reagan, 1995). The term 'd/Deaf' is commonly used to refer to the community as a whole (Young & Hunt, 2011).

Most of the everyday challenges of d/Deaf persons stem from their poor quality of communication with hearing persons (WHO, 2015). Communication challenges affect various important facets of d/Deaf persons' lives including education, employment, as well as accessibility to both social and health services (WHO, 2015). d/Deaf persons communicate in several ways, including speaking and lip-reading, writing, and most commonly through sign language (Dougall & Fiske, 2008; WHO, 2015). Like verbal languages, sign languages are fully developed languages with complex grammar and formal structures (MacDougall, 2012). Sign language is not universal and exhibits linguistic variations, inspired from the local spoken languages (MacDougall, 2012). For example, Langue des Signes Quebecoise (LSQ) is the sign language associated with the French-speaking population of the province of Quebec in Canada. LSQ is different from the American Sign Language (ASL) which is the sign language linked to American English (MacDougall, 2012).

Although, d/Deaf persons have developed various methods to communicate effectively, communication with hearing persons remain an on-going challenge for them (WHO, 2015). In the context of health care, numerous studies have shown that d/Deaf persons experience several barriers when accessing health care services (Barnett et al., 2011; Harmer, 1999; Scheier, 2009; Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006). The main barriers identified in the literature include: communication barriers between d/Deaf persons and health care professionals, negative attitudes of health care professionals, and lack of knowledge by health care professionals regarding the realities of the d/Deaf community (Parise, 1999). A large body of evidence confirms that communication in health care settings for d/Deaf persons can be significantly improved by using a professional sign language interpreter (Iezzoni, 2004; Parise, 1999; Steinberg et al., 2006; A. Steinberg, Wiggins, Barmada, & Sullivan, 2002). In Canada, following the Eldridge v. British Columbia decision, the Supreme Court of Canada mandated free SL interpretation services for all services under the Canada Health Act (Parise, 1999). Oral health care services, however, are not part of this Act. Therefore, d/Deaf persons in Canada are not entitled to receive free of cost interpretation services during dental appointments.

In contrast to general health care, there is a dearth of research on the topic of access to oral health services for d/Deaf persons. There is no baseline data regarding oral health of, and oral health care for, d/Deaf persons in Canada. However, previous studies from other parts of the world have shown that d/Deaf persons suffer from poorer oral health status compared to their hearing counterparts in the population (Al Sarheed, Bedi, & Hunt, 2003; Kanika, Kalpana, Meenu, & Mohita, 2011; Shahrabi, Mohandes, & Seraj, 2007). According to the Canadian Dental Association, adequate access to oral health care is fundamental for establishing diagnosis, preventing oral diseases, and providing comprehensive care, which ensures good oral, as well as general health of an individual (CDA, 2010). Previous studies have pointed out that the poor oral health status of d/Deaf persons could be associated with their inadequate access to oral health care services (Ajami, Shabzendedar, Rezay, & Asgary, 2007; Kanika et al., 2011; Oredugba, 2004). Yet, very little is known regarding the barriers that d/Deaf persons face when accessing oral health care services.

Given the lack of free sign language interpretation services for dental appointments in Canada, the d/Deaf population, in general, is vulnerable to poor access to oral health care. Moreover, the d/Deaf ASL users living in Quebec, a French-speaking province, may encounter additional barriers when accessing oral health care services associated with being a linguistic minority. Previous research has showed that the d/Deaf ASL users face more challenges, compared to the d/Deaf LSQ user, when accessing health care services in Quebec (Parise, 1999). For the purposes of clarity, I have used the term ‘Anglophone d/Deaf population,’ to refer to d/Deaf ASL users in Montreal. The purpose of this present study is to answer the following research questions: How do Anglophone d/Deaf persons experience access to oral health care services in Montreal? What are the barriers that the Anglophone d/Deaf population faces in their oral health care pathways? And what are the potential solutions to improve their access to oral health care services?

Chapter 2: Literature Review

2.1. Deafness and the d/Deaf community

2.1.1. Key terms and definitions

As Khang (2000) pointed out, there is no universally accepted definition of the term ‘deaf.’ Deafness has been defined in several ways. These definitions range from an audiological interpretation - the extent of hearing loss in a person, to a linguistic and cultural understanding of deafness - the ‘Deaf culture’ (Andrews et al., 2004). According to the World Health Organization (WHO, 2015) “a person who is not able to hear as well as someone with normal hearing – hearing thresholds of 25 dB or better in both ears – is said to have ‘hearing loss’” (WHO, 2015). The WHO have classified hearing loss into the following categories: mild, moderate, severe, or profound (WHO, 2015). According to this classification, the term ‘hard-of-hearing’ refers to persons who have mild to severe hearing loss, whereas the term ‘deaf’ refers to persons with either complete or profound hearing loss (WHO, 2015).

The term ‘Deaf culture’ refers to a distinct group of people within the deaf community who share similar practices, beliefs, and values (Andrews et al., 2004). Persons who associate themselves with the Deaf culture do not identify themselves as having a disability. Details regarding the Deaf culture are discussed below (section 2.1.4.1). To distinguish persons who consider themselves part of the Deaf culture, Woodward (1972) proposed the following convention: Deaf with a capital ‘D’ to refer to persons associated with the Deaf culture, and deaf with a lower case ‘d’ is used to denote deaf persons who do not relate with the Deaf culture (Young & Hunt, 2011). Following this convention, ‘d/Deaf’ is used as a collective term to refer to the community as a whole (Young & Hunt, 2011). From now onwards, I have followed the same convention throughout this thesis.

Lastly, the term ‘age at onset’ is used to refer to the age at which a person loses hearing. Persons who are either born d/Deaf, or those who lose hearing prior to the average age of language and speech acquisition (before 3 years of age), are referred to as ‘prelingually d/Deaf’ (Kaplan &

Puterman, 2010). In contrast, the terms ‘postlingually d/Deaf’, or ‘deafened,’ refers to persons who lose hearing after the development of speech and language (Barnett & Franks, 2002).

2.1.2. Demographics of the d/Deaf population: Globally, in Canada and in Quebec

Determining the accurate estimates of d/Deaf persons living in a particular area is a challenging process for various reasons (Khang, 2000). There is variability among the prevalence data on hearing loss across different surveys (Khang, 2000). Moreover, the figures presented in survey reports on the prevalence of d/Deafness are mostly underestimated as they tend to exclude certain groups within the d/Deaf community (CAD, 2012e; Woodcock & Pole, 2007).

Khang (2000) pointed out two main reasons for the variability in prevalence data of on d/Deafness. First, the differences in the criteria for defining ‘hearing disability.’ The majority of the existing surveys have used either one or more of the following parameters to define hearing disability: 1) fence (the level of audiometric reading that confirms a significant hearing loss); 2) ear (whether or not one or both ears are included in the definition); and 3) audiometric test stimuli (speech or pure tones). Another factor contributing to the variability in survey findings is lack of a standard data collection tool. For example, both self-reported and audiometric measures are employed to determine the presence of hearing disability in a person.

Many d/Deaf advocacy groups claim that the actual count of d/Deaf persons is greater than what is stated in most survey reports (CAD, 2012e). The two main groups who are often excluded from the prevalence data on d/Deafness are: 1) the culturally Deaf persons; and 2) d/Deaf persons with low levels of literacy (CAD, 2012e). According to the CAD (2012e), since survey questions are simply designed to identify whether a person has hearing disability or not, they tend to exclude the culturally Deaf persons, as they do not identify themselves as persons with disabilities (CAD, 2012e; Young & Hunt, 2011). The following excerpt is from the CAD’s (2012e) official website:

> For example, asking if we “have difficulty hearing” often provokes the response, “No, we just don’t hear!” And asking if we “have difficulty communicating with others” gets the reply, “No, my Deaf friends and I have no problem communicating because we all use Sign!” These replies may be true, but they result in Deaf people being classified as “hearing” and thereby eliminated from

> statistics on deafness. The terminology used in these questions thus sabotages the purpose of the questions.

The second group to be commonly excluded from the prevalence data on d/Deafness are people with low literacy levels. Since survey questionnaires are usually administered in a written format, persons with low literacy are not able to respond in writing. As a consequence, they are often not reported in the prevalence data on d/Deafness (CAD, 2012e). Given these complexities, it is important to interpret the prevalence data regarding d/Deafness with caution. Before interpreting the d/Deaf prevalence data, researchers and policy makers should consider the methodological shortcomings in existing surveys.

2.1.2.1. Global demographics

The World Health Organization (2015) defines ‘disabling hearing loss’ as “hearing loss greater than 40dB in the better hearing ear in adults, and a hearing loss greater than 30dB in the better hearing ear in children” (para.1). The WHO (2015) recently conducted a survey to find the number of persons with disabling hearing loss around the world. As the data collection tool, they employed audiometric testing to determine if a person has a hearing loss, and if yes, to what extent (WHO, 2015). According to the findings of this survey, there are approximately 360 million people in the world living with disabling hearing loss of varying degree (WHO, 2015).

2.1.2.2. In Canada and in Quebec

In 2006, Statistics Canada designed and conducted the Participation and Activity Limitation Survey (PALS) (Statistics Canada, 2006b). The purpose of this survey was to gather information “on adults and children who have an activity limitation, that is, whose everyday activities are limited because of a condition or health problem” (Statistics Canada, 2006b, p. 1). In PALS, ‘hearing limitation’ was defined as “difficulty hearing what is being said in a conversation with one other person, in conversation with three or more persons, or in a telephone conversation” (Statistics Canada, 2006c, p. 30). In contrast to the WHO, PALS used a ‘self-reported’ scale to determine the presence and extent of ‘hearing limitation.’ According to the PALS results, there are an estimated 1.3 million persons (0.4% of the Canadian population), aged 15 and above, with different degrees of hearing limitation in Canada (Statistics Canada, 2006a). These figures include approximately 83,160 d/Deaf persons, with 36,700 prelingually d/Deaf and 46,390 postlingually d/Deaf (Statistics Canada, 2006a). In Quebec, there are almost 26,000 d/Deaf persons, however the breakdown between the prelingually and postlingually d/Deaf persons is unknown (Statistics Canada, 2006a).

2.1.3. Socioeconomic status of d/Deaf persons in Canada

d/Deaf persons have a lower employment rate as compared to the hearing people in Canada (Statistics Canada, 2006a). According to the literature, there are two main reasons for this: the first is the low literacy of d/Deaf persons (Literacy Ontario., 1998; WHO, 2015), and the other is the negative attitudes of employers towards hiring d/Deaf persons (CAD, 2012b). According to the PALS survey, the highest level of education of almost 50% of the Canadian population with hearing limitation is high school or below (Statistics Canada, 2006a). The CAD suggests that the main reason for these low levels of literacy amongst d/Deaf persons in Canada is their inadequate access to quality education, delivered through sign language (CAD, 2012d). Consequently, the average literacy level of adult d/Deaf persons, both in the US and Canada, is between grade three to grade five level equivalent (Khang, 2000).

In addition and perhaps related to education issues, d/Deaf persons face difficulties in obtaining employment. As mentioned earlier, employers have negative attitudes towards hiring d/Deaf persons for various reasons. According to the CAD (2012b) employers hesitate to hire d/Deaf persons as they feel that communicating with a d/Deaf employee would be highly challenging. Further, they also believe that accommodating the communication needs of a d/Deaf employee might pose them financial constraints (CAD, 2012b). Consequently, as highlighted in the PALS survey (2006a), almost half of d/Deaf Canadians, between the ages 15 to 64 years, are not in the labor force; they are either unemployed or retired. Also, in the same survey, the employed d/Deaf Canadians reported that they did not have ideal working conditions for several reasons including lack of career growth and work place discrimination (Statistics Canada, 2006a).

2.1.4. Cultural and linguistic aspects of d/Deafness

2.1.4.1. Deaf culture

In the past, d/Deafness was viewed as a physical impairment comparable to other disabilities, such as, blindness and cognitive impairment (Jones, 2002). Over the years, this notion has changed dramatically, especially with the rise of the cultural understanding of d/Deafness. In recent times, many d/Deaf persons view 'Deafness' as a culture rather than a disability (Young & Hunt, 2011).

As Jones pointed out (2002), "particularly within the past few decades, proponents of deafness as a culture have asserted that deafness is not a pathology and therefore does not need to be 'fixed'" (pg. 51-60). Indeed, some d/Deaf persons do not seek medical assistance to restore hearing. They believe that d/Deafness provides them with an identity, a lifestyle, which would be compromised if they became hearing (McIlroy & Storbeck, 2011). The proponents of this ideology are known as the culturally Deaf persons. As noted earlier, the common way to distinguish the culturally Deaf persons is by writing 'Deaf' with a capital 'D' (MacDougall, 2012).

Because they communicate in a distinct language (sign language) and have shared experiences of living in a hearing society, shared history, and unique institutions (Deaf clubs) (Sparrow, 2005), Deaf persons argue that they are comparable to other cultural groups (Andrews et al., 2004). As the CAD (2012a) stated, "a culture is generally considered distinct when it has its own unique language, values, behavioral norms, arts, educational institutions, political and social structures, organizations, and "peripherals" (such as ethnic clothing, rituals, or special/unusual possessions)" (p. para. 3). By this definition, Deaf persons have a distinct culture which constitutes several of these elements including: sign language as the first language; Deaf schools and universities; Deaf theatre; political and social structures including several national and international Deaf organizations; and so forth (CAD, 2012a). The culturally Deaf persons consider someone to be part of the Deaf culture based on his or her views on d/Deafness, degree of involvement with the local Deaf community, and sign language proficiency (CAD, 2012a). According to a survey conducted by the CAD (2012e), there are almost 350,000 culturally Deaf persons in Canada.

2.1.4.2. Oralism

In contrast to the Deaf culture, ‘Oralism’ promotes oral education (lip-reading and speech training) for d/Deaf children (MacDougall, 2012). The major driving force for this view is the proposition that d/Deaf persons should ‘speak and hear’ in order to integrate into the majority hearing community (MacDougall, 2012). The concept of Oralism was first introduced and implemented by Alexander Graham Bell in the United States (MacDougall, 2012). Bell strongly opposed the use of sign language because he believed that signing would hinder the development of speech in d/Deaf children. According to MacDougall (2012), even though contemporary linguists recognize that sign languages have structural qualities comparable to spoken languages, oralists continue to fear that sign language will interfere with the linguistic development in d/Deaf children (p. 66). d/Deaf persons who prefer using oral methods of communication over sign language are distinguished from the Deaf culture by either using lowercase ‘d’ for deaf, or by referring them as ‘orally deaf’ (Andrews et al., 2004).

2.1.5. Mode(s) of communication

According to the WHO (2015), one of the major impacts of hearing loss on d/Deaf persons is their poor quality of communication with hearing people. To counter these communication challenges, various methods of communication have been developed for d/Deaf persons (Andrews et al., 2004). Broadly speaking, d/Deaf persons use the following methods to communicate: sign language, speaking and lip-reading, and writing (Andrews et al., 2004; MacDougall, 2012). Each d/Deaf person has a preferred way to communicate, influenced by his or her age of hearing loss, education and upbringing (Andrews et al., 2004; Young & Hunt, 2011).

As noted earlier, the prelingually d/Deaf persons are those who are either born d/Deaf or lose hearing before acquiring language and speech (before age three). Therefore, pre-lingually d/Deaf children often start communicating in sign language from an early age, especially if their parent(s) are also d/Deaf (Andrews et al., 2004). As most of the prelingually d/Deaf persons only communicate in sign language, they have very little opportunities to interact with hearing people (Andrews et al., 2004; Young & Hunt, 2011). Consequently, they mainly socialize with other d/Deaf persons who also communicate in sign language (Barnett & Franks, 2002). Also, it is worthy to note that the prelingually d/Deaf persons are the ones mainly associated with the Deaf culture (Andrews et al., 2004).

In contrast to the majority of prelingually d/Deaf persons who mostly communicate in sign language, the postlingually d/Deaf persons communicate in multiple ways (Andrews et al., 2004). Postlingually d/Deaf persons are those who become d/Deaf after the acquisition of speech and language (after age three) (Barnett & Franks, 2002). Many postlingually d/Deaf children would have started schooling when they were able to hear and speak. Accordingly, the postlingually d/Deaf children would then continue to attend mainstream schools where they regularly interacted with other hearing children. (Andrews et al., 2004). They thus often receive training to speak, lip-read, and some, with the help of hearing devices (e.g., cochlear implants), are also able to hear to some extent (Andrews et al., 2004). Therefore, the postlingually d/Deaf persons often integrate better with hearing persons as compare to those who are prelingually d/Deaf (Barnett & Franks, 2002).

2.1.5.1. Sign Language and interpretation

According to Andrews and Weiner (2004), sign language is the most common mode of communication for d/Deaf persons around the world. Sign language is a visual language composed of hand signs, facial expressions, and body postures (WFD, 2015). Akin to spoken language, sign language is a fully developed language, with complex grammar, and formal language structures (MacDougall, 2012). Sign language is not universal; it varies according to the local spoken language (MacDougall, 2012). American Sign Language (ASL) is the most common sign language used in the US and the English-speaking d/Deaf community in Canada (MacDougall, 2012; WFD, 2015).

d/Deaf persons communicate in sign language with hearing persons through an interpreter who interprets sign language into spoken language and vice versa (Khang, 2000). A trained interpreter should interpret everything that is spoken in the presence of a d/Deaf person without altering the content of conversation (Khang, 2000). The goal of effective interpretation is to convey both messages and feelings of d/Deaf persons as accurately as possible. In the absence of a professional interpreter, d/Deaf persons tend to use family members as interpreters (Lieu, Sadler, Futterton, & Stohlman, 2007; Wood, 2002). However, family members are not usually proficient in sign language, nor trained to interpret; thus they are often not effective interpreters (Lieu et al., 2007; Scheier, 2009; Steinberg et al., 2006).

2.1.5.2. Lip-reading and speech

Lip-reading is a technique used for visually interpreting speech by observing the lip and tongue movements, facial expressions, and body language of a person (CDC, 2015). Although many d/Deaf persons use lip-reading for understanding speech, it is only effective about 30 to 40 percent of the time (Khang, 2000). As DiPietro and colleagues pointed out (1981), a combination of both physical and linguistic factors makes it challenging for d/Deaf persons to lip-read.

The major linguistic barriers to lip-reading include the following: 1) letters and words that appear identical on lips; and 2) foreign accents (DiPietro et al., 1981) . Many letters and words in English language may appear identical on lips, and therefore, lip-readers might find it difficult to distinguish these words and letters from one another (CDC, 2015; Khang, 2000). Example of letters that appear identical on lips include ‘p’ and ‘b’, ‘f’ and ‘v,’ and ‘t’ and ‘d’ (CDC, 2015). Understanding speech of persons with foreign accents is another barrier to lip-reading. This is because persons with foreign accents pronounce English vowels and syllables using different mouth shapes than native English-speakers (Campbell, Zihl, Massaro, Munhall, & Cohen, 1997). Therefore, it is difficult for d/Deaf persons to match their lip movement with a particular word or letter (Campbell et al., 1997). Further, common physical factors impede the lip and facial view, such as beards and moustaches inadequate lighting, and facial masks (e.g., in a dental office) (DiPietro et al., 1981; Iezzoni, 2004). To enable lip-reading, hearing persons should therefore try to speak clearly and maintain eye-contact with d/Deaf persons at all times (CDC, 2015) and be aware of physical barriers.

In addition to lip-reading, d/Deaf persons who receive speech-training may also communicate via speaking (Khang, 2000). However, many d/Deaf persons are reluctant to speak as they cannot modulate their own voices; voice modulation requires a person to hear his or her own speech, in order to adjust their vocal tones accordingly (Khang, 2000). Therefore, to avoid the embarrassment of sounding strange to hearing people, many d/Deaf persons do not prefer speaking (Khang, 2000). Moreover, the culturally Deaf persons strongly oppose the use of speech as a method of communication. As noted earlier, the culturally Deaf persons strive for the acceptance of sign language in the society fearing that the use of oral modes of communication pose a threat to the recognition of Deaf culture (Burch, 2000; MacDougall, 2012).

2.1.5.3. Writing

Another way that d/Deaf persons communicate with hearing people is by writing (Andrews et al., 2004). While it may appear as a convenient method of communication, writing has its own limitations. First of all, writing is a slow process: when two people communicate by writing, each has to wait for his or her turn to respond (Khang, 2000). In the context of health care, many health care professionals prefer writing short versus long messages to save time (Khang, 2000). Consequently, d/Deaf persons often do not completely understand what the health care providers are try to convey in writing (Khang, 2000). Also, writing is not a feasible option for many d/Deaf persons because of their low literacy. Given these realities, writing should not be considered as a preferred method to communicate with d/Deaf persons.

2.2. Oral health profile of the d/Deaf population

2.2.1. Oral health of d/Deaf persons in comparison to the hearing population

The current literature regarding both oral health and oral health care of d/Deaf persons is mainly focused on the pediatric population. Also, there is no baseline data regarding the oral health of d/Deaf population in Canada. In terms of oral health, previous studies have confirmed that d/Deaf children and adolescents have higher rates of oral diseases compared to their hearing counterparts in the population (Ajami et al., 2007; Vichayanrat & Kositpumivate, 2014; Wei, Wang, Cong, Tang, & Wei, 2012). Several studies have reported that the oral hygiene levels of d/Deaf children are poorer than hearing children (Ajami et al., 2007; Jain et al., 2008; Shyama, Al-Mutawa, Morris, Sugathan, & Honkala, 2001; Wei et al., 2012). Poor oral hygiene is a known risk factor for both periodontal diseases and dental caries (Amarasena, Ekanayaka, Herath, & Miyazaki, 2002; Loesche, 1996). As a consequence of their poor oral hygiene, d/Deaf children and adolescents have a higher prevalence of dental caries than their hearing peers (Jain et al., 2013; Kamatchy, Joseph, & Krishnan, 2003; Wei et al., 2012). For example, Wei and colleagues

(2012) conducted a study in China to compare oral health of d/Deaf high school students with that of hearing students. They found that the students who were d/Deaf had a 55.9% caries prevalence compared to only 13.8% in hearing students (Wei et al., 2012). Several other studies conducted in Iran, Saudi Arabia, India, and Tanzania have reported similar findings regarding differences in caries prevalence between the two populations (Ajami et al., 2007; Al-Qahtani & Wyne, 2004; Jain et al., 2013; Simon, Matee, & Scheutz, 2008).

Appropriate oral hygiene practices (e.g., brushing, flossing), and healthy dietary habits are the key to good oral health (CDA, 2010). Previous studies have found a lack of oral health knowledge and poor oral hygiene practices amongst d/Deaf children and adolescents (Oredugba, 2004; Wei et al., 2012). Oredugba (2004), for instance, conducted a study to assess the oral health knowledge, dietary habits and oral hygiene practices of a group of Nigerian d/Deaf adolescents. He found that d/Deaf adolescents had very little knowledge regarding both the causes of tooth decay, as well as the harmful effects of sweets and other 'cariogenic' food (Oredugba, 2004). Participants in his study reported that they snacked frequently on soft drinks, biscuits, and sweets, all known to promote tooth decay (Oredugba, 2004). Similarly, Wei and colleagues (2012) assessed and compared the prevalence of caries between a group of Chinese d/Deaf adolescents and their hearing peers. They found that the higher prevalence of caries amongst the d/Deaf adolescents group was associated with high frequency of consuming desserts and carbonated drinks (Wei et al., 2012).

According to Sandeep and colleagues (2014), the dearth of appropriate oral health promotion tools, tailored to the communication needs of d/Deaf persons, is a major reason for the lack of oral health awareness amongst d/Deaf persons (Sandeep et al., 2014). To counter this problem, Sandeep and colleagues (2014) developed and evaluated an oral health awareness tool constituting videos of oral hygiene instructions specifically produced for d/Deaf and hard-of-hearing children in India. They found that the visual tool played a significant role in raising oral health awareness amongst d/Deaf and hard-of-hearing children, indicated by improvements in their oral hygiene status within few weeks (Sandeep et al., 2014).

2.2.2. Oral health of d/Deaf persons in comparison to other disability groups

Several studies have compared the oral health status of d/Deaf children with two other disability groups, that is, either with children with intellectual disabilities and/or children who are blind (Ajami et al., 2007; Al-Qahtani & Wyne, 2004; Al Sarheed et al., 2003; Reddy, Kshitij, Ajay, Ninad, & Reddy, 2013; Shyama et al., 2001). Previous studies conducted in Iran and Saudi Arabia have found that children with intellectual disabilities have a higher prevalence of caries as compared to children who are d/Deaf (Ajami et al., 2007; Al-Qahtani & Wyne, 2004). According to Ajami and colleagues (2007), d/Deaf children have a higher cognitive functioning as compared to children with intellectual disabilities, thereby helping them to learn and apply oral hygiene techniques in a more effective way. Moreover, studies comparing oral health of d/Deaf children with children who are blind have reported a higher prevalence of oral diseases in the blind population (Ajami et al., 2007; Sanjay et al., 2014; Singh, Kaur, Gumber, & Kaur, 2012). Reddy and colleagues (2013) pointed out that children who are blind generally tend to have poorer oral health than d/Deaf children since they cannot visualize the act of tooth-brushing, thus, making them more prone to oral diseases.

2.3. Access to oral health care services for the d/Deaf population

2.3.1. Definition of Access

According to Guay (2004), the current concept of 'access to oral health,' extends well-beyond its traditional meaning. As Ajayi & Arigbede (2012) stated, "The traditional concept of access to oral health care refers to a patient's ability to obtain or make use of oral health care" (p. 507). Accordingly, factors external to the patients, such as, availability of dental workforce and the ability to pay for oral health care services were the primary determinants of access (Ajayi & Arigbede, 2012; Guay, 2004). The present-day concept of access to oral health care however takes into account factors internal to the patients; for example, oral health perceptions, perceived need for care, cultural aspects, language barriers and so forth (Ajayi & Arigbede, 2012; Guay, 2004). This understanding has led to the development of a multifaceted concept of access to care constituting the following five dimensions: availability (the supply of practitioners), accessibility (transportation, distance, and cost), accommodation (ability of service providers to accommodate patient needs), affordability (ability to pay), and acceptability (patients' attitude towards offered services) (Penchansky & Thomas, 1981). All these factors are mutually dependent, and therefore should be considered when defining access to care (Penchansky & Thomas, 1981).

2.3.2. General health care experiences of the d/Deaf population

Although oral health care literature is limited on this topic, several studies exist regarding access to general health care for d/Deaf persons (DiPietro et al., 1981; Emond et al., 2015; Harmer, 1999; Steinberg et al., 2006). A large body of evidence suggests that d/Deaf persons encounter several barriers when accessing health care services, the most common of which include the following: 1) communication difficulties, 2) financial challenges, and 3) the negative attitudes of health professionals (Emond et al., 2015; Harmer, 1999; Parise, 1999; Scheier, 2009). Understanding the health care issues of d/Deaf persons may provide useful insights to their oral health care problems. This is because oral health has the same social, economic and behavioral determinants as general health (CAHS, 2014).

2.3.2.1. Communication difficulties

Communication is central to the process of health care. Patients need to communicate effectively with health care providers to obtain appointments, to share medical history, or even to consent to procedures (Dougall & Fiske, 2008; Ubido, Huntington, & Warburton, 2002). Moreover, the accurate diagnosis of a health condition, and the subsequent therapy, highly depends on the quality of doctor-patient communication (DiPietro et al., 1981; Ubido et al., 2002; Woodcock & Pole, 2007). Communication difficulties are the most significant barriers for d/Deaf persons when accessing health care services for various reasons (Emond et al., 2015; Harmer, 1999; Scheier, 2009). Poor access to sign language interpretation services (Harris & Bamford, 2001; Ubido et al., 2002), as well as a dearth of health professionals proficient in sign language, further complicates the issues of communication for the d/Deaf community (Steinberg et al., 2006; A. G. Steinberg, Sullivan, & Loew, 1998). Moreover, several studies have reported that d/Deaf persons lack understanding of many commonly used medical terms (e.g., names of diseases and body parts) (Badger & Jones, 1990; Gibbons, 1985; Harmer, 1999). This lack of understanding is due to limitations in the sign language vocabulary, which is devoid of several medical terms, such as, ‘glaucoma,’ ‘bowel,’ ‘fertility drug’ and so forth (Ubido et al., 2002). Consequently, d/Deaf persons often misunderstand their diagnosis, miss health care appointments, and are subject to medical errors (Scheier, 2009).

2.3.2.2. Financial barriers

In addition to communication difficulties, financial issues further complicate the process of health care for the d/Deaf population (Kuenburg, Fellinger, & Fellinger, 2016; Parise, 1999; Shah & Priestley, 2001). According to Harmer (1999), health care providers require more time to work with d/Deaf patients in comparison to hearing patients. This additional time is financially restraining for many physicians, especially those who work on 'fee-for-service' basis (DiPietro et al., 1981). According to Steinberg and colleagues (2002), having a professional sign language interpreter ensures effective communication between physicians and d/Deaf patients. However, paying high costs of interpretation services adds to the overall expenses of the health care system (Scheier, 2009).

2.3.2.3. Lack of awareness and negative attitudes of health professionals

Lack of awareness by health care professionals regarding d/Deafness and the d/Deaf community is another significant barrier for d/Deaf persons' access to health care services (Harmer, 1999; Meador & Zazove, 2005; A. Steinberg et al., 2002). Several studies have found that health professionals have poor knowledge regarding health care needs of the d/Deaf population, which presents several challenges for the d/Deaf community (Emond et al., 2015; Iezzoni, 2004; Parise, 1999; Smeijers & Pfau, 2009). Firstly, health care professionals lack an understanding regarding appropriate methods to communicate with a d/Deaf person, leading to inadequate communication (Ebert & Heckerling, 1995; Iezzoni, 2004; Kuenburg et al., 2016). Other significant barriers include negative attitudes of health professionals (Parise, 1999; Steinberg et al., 2006; Witte & Kuzel, 2000). Steinberg and colleagues (2002) conducted a qualitative study with a group of d/Deaf women to explore their health care experiences: participants experienced negative attitudes, describing health care professionals as insensitive, paternalistic, and authoritative (A. Steinberg et al., 2002). Another study conducted in a mental health care facility reported similar findings (A. G. Steinberg et al., 1998). As pointed out by several authors (Harmer, 1999; Steinberg et al., 2006; Witte & Kuzel, 2000), the negative attitudes of health care professionals might be due to lack of training in medical schools, coupled with the prejudice they hold towards disability in general.

2.3.3. Oral health care issues of the d/Deaf population

Data specific to oral health care of the d/Deaf population, specifically adults, is very limited. Champion and Holt (2000) conducted a study in the UK to explore barriers to oral health care for the d/Deaf and hard-of-hearing children. They found that the vast majority of their participants, approximately ninety-eight percent, visited the dentists regularly (Champion & Holt, 2000). Despite their regular dental attendance, parents pointed out numerous challenges their children faced while accessing oral health care: challenges in making appointments, communicating with the dentists, being called from the waiting area, and comprehending the process of care (Champion & Holt, 2000).

Although this study identified important barriers that d/Deaf persons might face when accessing oral health care, its results are limited. For instance, the sample constituted a mix of both d/Deaf and hard-of-hearing children (Champion & Holt, 2000). While both these populations share a common characteristic, the loss of hearing, they are considerably different. They communicate in their own ways, receive education differently, as well as hold separate worldviews on hearing loss (J. Andrews, I. Leigh, & M. Weiner, 2004; Barnett, 2002). Therefore, the study is limited in highlighting the unique problems of each population. Further, since the questionnaires were answered by the parents (Champion & Holt, 2000), this study excluded the direct ‘voice’ of the children themselves. Lastly, findings of this study do not explain the reasons, the ‘whys’ and ‘hows,’ behind the enumerated barriers that participants faced.

2.3.4. Dental education

A recent survey conducted in United States and Canadian dental schools revealed that the majority of schools in these countries do not provide sufficient training to students to care for persons with disabilities (Schwenk, Stoeckel, & Rieken, 2007). Another study found that only 53% of dentists in the United States had received ‘some level’ of training on providing care to persons with disabilities (Romer, Dougherty, & Amores-Lafleur, 1999). Typically, this training constitutes less than five hours of didactic, and even fewer hours of clinical training, and real-time exposure to persons with disabilities (Romer et al., 1999). Because the majority of dental schools in North America do not have a ‘special patient care clinic,’ dental students tend to refer persons with disabilities to other specialist departments (e.g., pediatric dentistry) within the university (Schwenk et al., 2007). This lack of training has important consequences since dentists who lack such training are less likely to accept persons with disabilities as patients (Rashid-Kandvani, 2013).

Al Sarheed and colleagues (2001) conducted a study in Saudi Arabia to assess the willingness of dentists to provide care to children with sensory disabilities. They found that dentists who received training to provide care for persons with disabilities, as well as those who were practicing for a relatively longer time, had positive attitudes towards providing care to the latter (Al Sarheed et al., 2001). The same authors also conducted another study to explore willingness of dentists to specifically provide orthodontic treatment to these patients (Al Sarheed, Bedi, Al Khatib, & Hunt, 2006). They found that dentists preferred providing orthodontic treatment to persons who are d/Deaf, rather than those who are blind (Al Sarheed et al., 2006). According to Al Sarheed and colleagues (2006), the dentists’ hesitation to provide orthodontic care to children who are blind possibly reflected their prejudice towards blindness in general. One of the indications for orthodontic treatment is to enhancing the facial and dental appearance of a person (Turley, 2015). Therefore, as Al Sarheed and colleagues (2006) speculated, these dentists might feel that such treatment is unnecessary for persons who cannot see their aesthetic changes for themselves.

2.3.5. Oral health care delivery system in Canada and in Quebec

The recent Canadian Academy of Health Sciences (CAHS) report revealed that only 4.9% of oral health care in Canada is funded publicly, and that 51% of Canadians pay either through private or special public dental insurance (e.g., persons on social assistance) (CAHS, 2014). Accordingly, almost half of Canadians are not covered under any insurance plan, and must pay ‘out-of-pocket’ for their oral health care (CAHS, 2014). Regardless of the source of funding, almost all oral health care services in Canada are delivered in private dental offices (CAHS, 2014). The local regulatory body pays the dentists on behalf of patients, covered under the public insurance plan (CAHS, 2014). The proportion of public funding varies according to the province and territory, ranging from 1.5% in Ontario to 77% in Nunavut (Yalnizyan & Aslanyan, 2011).

In Québec, public dental insurance is funded by the Régie de l'assurance maladie du Québec (RAMQ). For all Québec residents, RAMQ covers hospital-based oral surgical procedures (e.g., bone graft, drainage of abscess, reduction of a fracture) (RAMQ, 2015). With respect to children under the age of ten, the public insurance program covers cleaning, fluoride application, as well as most of the basic dental procedures (e.g., exams, fillings, and extractions) (RAMQ, 2015). Further, for persons on social assistance, RAMQ covers exams, fillings, extractions, and complete and partial dentures. However, endodontic treatment and fixed prosthesis (e.g., crowns and bridges) are not included in their insurance plan (RAMQ, 2015). Moreover, the Aboriginal community members, a socially marginalized population, have exclusive dental insurance plans, which covers a variety of services in Quebec (CAHS, 2014; RAMQ, 2015). However, even though persons with disabilities are vulnerable to poor oral health, they are not covered by any special public dental insurance plan (CAHS, 2014).

2.3.6. Legal issues in oral health care of the d/Deaf population in Canada

As pointed out in several studies, communication in health care settings for d/Deaf persons is primarily dependent on adequate access to professional sign language (SL) interpretation services (Harmer, 1999; Scheier, 2009; Steinberg et al., 2006; Zazove et al., 1993). In 1997, following the Eldridge v. British Columbia decision, the Supreme Court of Canada mandated free SL interpretation services for all services covered under Canada Health Act (Parise, 1999). However, since oral health care services do not constitute this Act, d/Deaf persons are required to cover the cost of interpretation in oral health care by themselves.

2.4. Summary of the literature review

Previous studies have shown that d/Deaf persons around the world have poorer oral health than their hearing counterparts in the population due to both lack of oral health knowledge and limited access to oral health care services. Although the current body of evidence extends our understanding about the oral health status of d/Deaf persons, there is a dearth of research about the barriers d/Deaf persons face when accessing oral health care services. Moreover, previous oral health studies have only focused on the children and adolescent d/Deaf populations. Exploring the issues of d/Deaf adults could be particularly important as research has demonstrated that this group faces more problems in accessing services than children. According to Stewart and colleagues (2006) when youth with disabilities transition into adulthood, they find it difficult to coordinate services, including health care, independently. Yet, to my knowledge, no previous studies have looked into both the oral health profiles and access to oral health care of adult d/Deaf persons.

The adult d/Deaf population in Canada is vulnerable to poor access to oral health care because they can face both communication as well as financial challenges on their pathways to oral health care. Although the Canadian government provides an interpreter to d/Deaf persons for their health care appointments, the d/Deaf are not entitled to receive free interpretation services for dental appointments. Further, the majority of d/Deaf persons constitute the low-income groups in Canada. Thus, it could be difficult for them to cover the cost of interpretation for their dental appointments. Moreover, as noted earlier, the oral health care system in Canada is mostly funded privately. As a result, given their financial difficulties, most d/Deaf persons might find it difficult to afford the cost of dental care 'out-of-pocket.' Additionally, d/Deaf persons are also at risk of encountering dental professionals who have little awareness about their communication needs. As described by previous studies, one of the most significant barriers for d/Deaf persons in accessing health care services is the lack of awareness by health professionals about the realities of d/Deafness (e.g., Deaf culture). In line with these findings, several studies have found that dental professionals lack the willingness, knowledge and the skills to provide care to persons with disabilities.

In the context of Quebec, d/Deaf persons who communicate in American Sign Language (ASL) are likely to encounter more barriers than those common to all d/Deaf persons in Canada. In addition to being a minority by their disability status, the Anglophone d/Deaf population in Quebec are also a linguistic minority. This is because the official spoken-language in Quebec is French, and therefore ASL, which is associated with American English, is a minority language in Quebec. As a result, linguistic barriers that the Anglophone d/Deaf population face are comparable to the English-speaking communities in Quebec. Parise (1999),who conducted a study to explore the general health care accessibility issues of the d/Deaf ASL users in Quebec, confirmed that linguistic barriers exist for this population when accessing general health care services. The two main linguistic barriers that she highlighted were inadequate access to ASL interpreters working in Montreal and difficulties in reading lips of health professionals with French accents.

In the present study, therefore, I aimed to explore the answers to the following research questions: How do d/Deaf persons access oral health care services in Montreal? What are the barriers they face when doing so? How can we improve their access to oral health care services? To answer these questions, I chose focused ethnography with a participatory approach as the methodology to unveil the social, cultural, economic, and communication factors associated with access to oral health care services for the d/Deaf ASL users in the area of Montreal, Quebec, Canada.

Chapter 3: Methodology

In this chapter, I first describe the research approach and the theoretical and conceptual frameworks that I used to answer the main research question, "How do persons who are d/Deaf access oral health care services in Montreal?" Following, I provide a description of the chosen methodology, focused ethnography, with the multiple methods that I used to collect and analyze data. In the end, I discuss the methodological rigor and ethical considerations of this study.

3.1. Participatory research approach

In this study, I incorporated a participatory research approach throughout the research process. Participatory research is a "systematic inquiry, with collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting change" (p. 1927). Participatory approach empowers participants, by including them on equitable basis throughout the conduct of research. By doing so, participatory research enables participants to identify and solve issues that are important to them (Rashid-Kandvani, 2013). The major benefit of a participatory approach is that it integrates the 'real world' expertise of community partners, with the 'scientific knowledge' of researchers, thereby enhancing both the relevance of the findings, and the process of knowledge translation (Cargo & Mercer, 2008). I chose a participatory approach because it enabled me to collaborate with people directly affected by the issues of access to oral health care for the Anglophone d/Deaf community in Montreal.

3.1.1. Development of the advisory committee

To develop the study partnerships, beginning in September 2013 I started to form an advisory committee. For this process, I collaborated with three relevant groups: a d/Deaf advocacy organization, a local rehabilitation centre for d/Deaf persons, and health care researchers. As members of the advisory committee, representatives of these groups provided feedback during all stages of the research: from formulating research questions, to recruiting participants, to interpreting findings and planning knowledge translation at the end. This process took four months as follows:

Developing the study partnership was a lengthy process that required extensive research and networking. To begin, I made a list of organizations representing the Anglophone d/Deaf community in Montreal. I identified these organizations by searching the Internet and inquiring of colleagues and faculty members at the McGill Division of Oral Health & Society (OHS). Through this process, I identified that the most proactive organization working with the Anglophone d/Deaf community in Montreal was the MAB-Mackay Rehabilitation Centre, which provided adaptation, rehabilitation, and social integration services.

I therefore contacted the resident researcher and site representative at the MAB-Mackay, Dr. Walter Wittich. Via email, I provided him with a short description of my project, after which he invited me for a meeting to discuss the project with his team members, Mr. Jonathan Jarry, the research coordinator, and Ms. Ashanta Farmington, a social worker. During this meeting at the MAB-Mackay Centre, they agreed to take on role of a member within the advisory committee, which included assisting with the recruitment and providing space for interviews at the MAB-Mackay.

In addition, a colleague at the OHS, Ms. Carolina Pineda introduced me to Dr. Jennifer Paige MacDougall, Director of the Canadian Deafness Research & Technology Institute (CDRTI). Following correspondence, Dr. MacDougall invited me for a meeting during which she introduced me to the President of the CDRTI, Dr. Jamie MacDougall. Based on their extensive experiences regarding health care accessibility for the Anglophone d/Deaf community in Quebec, they joined the advisory committee. In addition to helping shape the research questions, they also agreed to assist with recruitment.

Lastly, while attending the “ASL Health Care Focus” course offered by Seeing Voices Montreal (SVM) at McGill University, I met Ms. Aselin Weng, the executive director of SVM. I invited her to a meeting during which I briefly described my project, and requested she join the advisory committee; she agreed.

3.1.2. Role of the advisory committee

In total, there were nine members on the advisory committee representing four different organizations: MAB-Mackay, CDRTI, SVM, and McGill Dentistry. I collaborated through individual meetings with representatives of each partner organization at different stages of the project. During initial meetings, members provided feedback to help define the scope of the research. In particular, the purpose of these early meetings was to articulate the research problem, develop the interview guide, and identify potential recruitment opportunities. Subsequent meetings were conducted to design a recruitment strategy, and help recruit professional ASL interpreters. Following the first four interviews with recruited participants, discussions were held to include additional questions in the interview guide to further address the issues faced by the Anglophone d/Deaf community in Montreal.

After the analysis of eight interviews, I requested feedback from the advisory committee on the interpretation of findings. After the end of all interviews and analysis, the advisory committee provided their input on possible avenues for knowledge translation, and the feasibility of implementing these activities. Examples of this feedback were the suggestion to include dentistry-specific case scenarios in the curriculum of the ASL 'healthcare focus' course held by the SVM at McGill University, and later to invite the course instructors to lecture to dental students on d/Deaf awareness and dentistry-focused ASL. In future, I plan to work with the relevant organizations to move these suggestions into actions. Table 1 summarizes the role of each participating organization in the project.

Table 1. Role of the Advisory Committee

	MAB-Mackay	CDRTI	SVM	McGill Dentistry
Choice of Methodology				✓
Facilitating Recruitment and Data Collection	✓	✓	✓	✓
Data Analysis		✓	✓	✓
Dissemination and KT	✓	✓	✓	✓

3.2. Theoretical framework

In disability studies, conventionally the personal tragedy theory has remained the dominant theory (Thill, 2015). Personal tragedy theory, also called the 'medical model of disability,' views issues of disability solely as a consequence of a person's physical impairment (Oliver, 1998). In doing so, it asserts that persons with disabilities are incapable of functioning in a manner considered 'normal' in society (Oliver, 1998). In this view, societies are primarily designed to accommodate needs of the able-bodied persons, where emphasis is laid upon 'molding' persons with disabilities to 'fit in' the society (Oliver, 1998). In other words, personal tragedy theory implies that persons with disabilities face difficulties performing activities only due to their physical impairments, which when fixed, could either reduce or resolve their problems. Accordingly, most health research, practice, and policy focuses on clinical diagnosis, treatment, and prevention of physical impairment. A classic example of such interventions, in context of d/Deaf persons, is the surgical placement of cochlear implant to restore hearing.

Although useful for understanding the medical aspects of disability, personal tragedy theory is limited in its scope when describing the complete range of issues surrounding disability. Increasingly, competing theories argue that personal tragedy theory, by focusing entirely on medical issues, neglects the role that social, environmental, and cultural factors play in limiting the daily activities of persons with disabilities (Zajadacz, 2015). For example, a wheelchair user cannot enter a building if there are stairs at the entrance. When interpreted through the medical model, one may explain this situation as the inability of the person to use stairs. Seen from another angle, installing a ramp removes the obstacle that sets the wheelchair user apart from able-bodied walkers (Rashid-Kandvani, 2013). Further, as pointed out by Rashid-Kandvani (2013, p. 4), "the medical model inherently defines behavior on a spectrum of 'normal' and 'abnormal' activities," such as hearing and using a hearing aid, respectively.

In comparison to the personal tragedy theory, the 'critical theory of disability' views issues of disability explicitly as the product of an unequal society (Hiranandani, 2005). Critical theory of disability is a variant of the 'critical social theory' developed by the Frankfurt School theorists in the 20th century (Corradetti, 2015). Critical theory aims to understand reasons behind 'human entrapment' in systems of domination, and strives to find solutions towards people's liberation (Horkheimer, 1982). The meaning of critical theory is derived from the Greek word κριτικός (kritikos), which means 'judgment' (Grenfell, 2010). In disability studies, critical theory asserts that persons with disabilities face difficulties because the system is designed to suit needs of the able-bodied persons in society (Hiranandani, 2005). Critical theory implies that disability, rather than only a physical impairment, is the loss of opportunity to participate in daily activities on equitable basis (Hiranandani, 2005). In this view, the focus is on exploring the shortcomings of the system in accommodating the needs of persons with disabilities (Hiranandani, 2005). Critical theory proclaims that disability is more of a societal than an individual problem. Accordingly, it calls for actions to modify the social and physical environment to fit the needs of person with disabilities. For instance, optimizing accessibility to services, and information, as well as strategies to counteract discrimination in various facets of life, including health care, could improve the quality of life for persons with disabilities (Hiranandani, 2005).

I used critical theory of disability as the theoretical framework to guide this research. As noted in Chapter 2, culturally Deaf persons are strong opponents of the medicalization of disability. As a result, they do not identify as 'hearing disabled,' but rather, through the use of sign language, recognize themselves as a cultural and linguistic minority (Andrews et al., 2004). Deaf persons assert that that their communication problems are not due to hearing loss, but rather because of the linguistic barriers created by the society itself (CAD, 2012a). For instance, culturally Deaf persons believe that with access to sign language interpreters, they would not face communication barriers (Andrews et al., 2004; CAD, 2012c). In this study using critical theory, one of my major aims was to explore and critique the ways society presented barriers in access to oral health care for d/Deaf persons.

3.3. Conceptual framework

In oral health research, various conceptual frameworks are commonly used to explain oral health care accessibility issues experienced by vulnerable populations (e.g., people living in poverty). A couple of examples of such frameworks include: Aday and Andersen's (1974) model of health care utilization, and Watt's (2012) framework of the social determinants of oral health inequalities. There is no specific framework in the literature that describes barriers to access to oral health care experienced by persons with disabilities, including d/Deaf persons. In this study, I therefore adapted Grembowski and colleagues' (1989) 'public health model of dental care process' to describe the oral health pathways of d/Deaf persons in particular. I adapted this model by combining my knowledge of the d/Deaf health care literature with the preliminary findings of this study.

Grembowski and colleagues (1989) originally developed their framework following an analysis of a comprehensive review of the oral health care utilization literature, constituting both empirical and theoretical studies. They founded this model on the following six premises revealed in their analysis:

1. “First, the model must reflect fundamental choices regarding the use of professional dental care.
2. Second, for those who choose to visit the dentist, the episode of care becomes the basic unit of analysis.
3. Third, the use of professional dental services is regarded not just as an outcome but as a decision-making process.
4. Fourth, the provider can influence an individual’s use of dental services throughout the decision-making process.
5. Fifth, the dental care process takes place within a larger social structure, which, in turn, places constraints on that process.
6. Sixth, from an economic and patient point of view, the chief reasons for dental visits are to maintain or improve oral health and quality of life, not the purchase of dental services per se” (pp. 443-445).

Furthermore, Grembowski and colleagues (1989) used Emerson’s (1976) social exchange theory to provide a structure for the development of this model. ‘Exchange theory’ was initially developed to explain interactions between individuals (Grembowski et al., 1989). Emerson (1976) later modified the exchange theory to resolve the logical issues in earlier works, subsequently proposing his modified version, namely the ‘social exchange theory.’ Justifying the use of social exchange theory in their model, Grembowski and colleagues (1989) stated that “power and dependence between individuals in an exchange are the centerpiece of Emerson’s approach, making it a useful tool for examining power imbalances in patient-provider relations” (p. 449).

Moreover, Grembowski and colleagues (1989) proposed that the nature of oral health care process should be “defined operationally by the pathway that patients traverse from start to end” (p. 445). They describe the use of oral health care services as a ‘decision-making’ process composed of the six distinct stages, namely: decision to visit a dentist; searching for a dentist;

oral examination; diagnosis and treatment planning; treatment or referral; and discharge. The path that an individual follows when accessing oral health care services is largely influenced by the interdependent decisions made by both the individual and the oral health care provider during each stage of the pathway. It is worth noting that these stages do not represent a linear process. Rather, taking into account the complex nature of the oral health care process, it is recursive, where individuals might move back and forth between various stages of oral health care depending on their individual circumstances. For example, for persons who decide to change their current dentist, they might go back to the stage of 'searching for a dentist' on their pathway. Decisions made during the oral health care process are mainly influenced by the personal characteristics of individuals and oral health care providers, as well as the environment they live in.

According to Grembowski and colleagues (1989), an individual's decision to initiate or continue the oral health care process depends on their sociodemographic characteristics, and their oral health beliefs. Compared to high-income individuals, persons with low-income tend to decide against visiting dentists, or even continuing the treatment process (Grembowski et al., 1989). Additionally, persons who have dental insurances are less hesitant to visit dentists as compared to those who pay for dental costs out-of-pocket (Grembowski et al., 1989). Lastly, individuals who have a positive attitude towards prevention of oral diseases are also more likely to visit the dentist and complete their treatment (Grembowski et al., 1989).

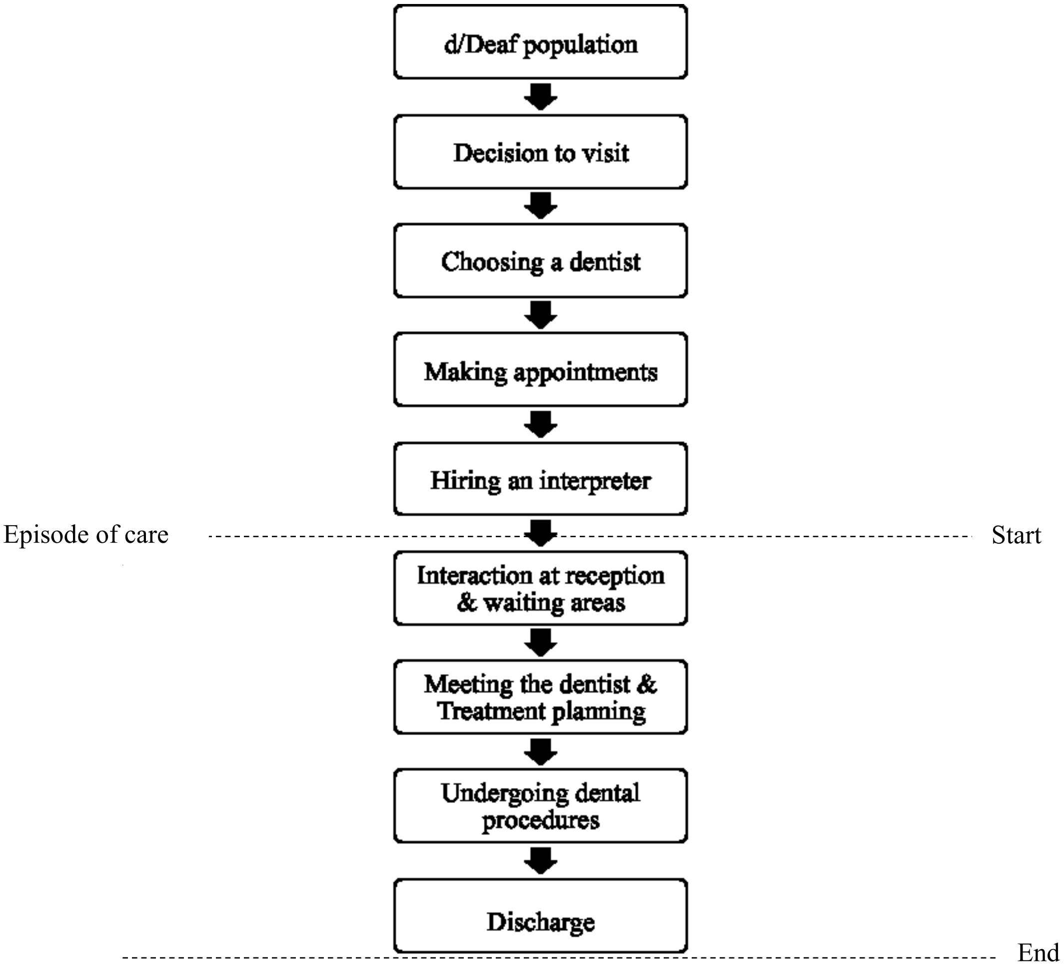
Moreover, oral health care providers' practice characteristics influence individuals' decisions regarding oral health care. According to Grembowski and colleagues (1989), dentists can offer favorable practice amenities (e.g., reduced waiting time, privacy, office décor, and convenient location) to attract and retain patients. Moreover, they pointed out that individuals prefer to visit dentists who interact with patients more than those who do not. Therefore, both practice amenities and dentists' approach to patient care are important factors that influence the decisions of individual.

Lastly, environmental factors including the supply of dentists and market prices for dental treatment further effects individual's oral health care process. According to Grembowski and colleagues (1989), if the supply of dentists in a community is greater than their demand, the patients are less dependent on one single provider. Therefore, when the numbers of dentists is more than their demand within a community, the dentists tend to be more accommodating to the needs of patients. In contrast, if there is a shortage of dentists, the dentists have more power than patients. However, if the dentist does not meet the needs of patients, the latter are more likely to withdraw from, or delay treatment as long as possible. Further, if the cost of treatment exceeds the perceived benefits of patients, patients might also search for cheaper alternative sources of care.

In summary, Grembowski and colleagues' (1989) model is based on the philosophy that oral health care is a "social process in which outcomes are determined normatively. A key element of this process is the exchange relation between the patient and the provider, which is structured by the environment as well as by the characteristics of the patient and the provider" (p. 480). With these founding principles, Grembowski and colleagues (1989) model is designed to understand the factors that lead patients to decide against seeking dental care, or opting out during a particular stage (if any) of their oral health care pathways.

In my adapted version, I modified the 'stages of oral health care' presented by Grembowski and colleagues (1989) The purpose of this modification was to create a framework that specifically explains the stages that d/Deaf persons commonly traverse on their pathways to oral health care. Another purpose was to take into account the most common events that influence d/Deaf persons' decision regarding initiating, or continuing, the process of oral health care. As described below (section 4.5), I used a qualitative research methodology constituting semi-structured interviewing with d/Deaf participants. Following the completion of the first four interviews, I specifically analyzed the data related to participants description of the stages they usually followed, or would follow ideally, as well as the events (e.g., interaction with office staff at reception and waiting areas) that participants considered important determinants of the outcomes of their oral health care process. I chose to first modify the framework after four interviews as I felt that I had adequate data to initiate the modification of the model. I continually confirmed the accuracy of the model with participants in future interviews; however, they did not suggest any changes, and agreed to the framework. Figure 1 presents the resultant model, including the typical stages/events of the oral health care pathways of d/Deaf persons. Further details regarding the use of this conceptual framework to guide the analysis are discussed in section 3.6.

Figure 1. Oral health care pathway of d/Deaf persons



3.4. Research design

I selected a focused ethnography research design with a participatory approach for this study. According to Roper and Shapira (2000), "Ethnography is a process of learning about people by learning from them" (p. 1). As an interpretive research methodology, ethnography is holistic in nature, having the context in which participants live and interact central to the research conducted (Boyle, 1994). In classic ethnographic studies, researchers study the entire social field, aiming to understand all aspects of a community's life. However, when investigating specific beliefs and practices regarding particular illnesses or specific healthcare processes as held by patients and practitioners, ethnography can be considered 'focused' (Higginbottom, Pillay, & Boadu, 2013).

Health-oriented focused ethnography focuses on the unique health-related issues of a discrete community within a specific context (Roper & Shapira, 2000). One of the main aims of focused ethnography is to understand the ways people from a particular community integrate health beliefs and practices into their daily life (Higginbottom et al., 2013; Roper & Shapira, 2000). Therefore I chose focused ethnography instead of classic ethnography: my study focuses on a specific aspect of the d/Deaf community, that is, the role of the society and the cultural beliefs of the community which influences access to oral health care for the Anglophone d/Deaf community in Montreal.

Focused ethnography is congruent with the theoretical orientation of this study. Focused ethnography seeks to understand the relationship between people and the environment in which they live, enabling an understanding of participants' perceptions regarding how social entities and processes impact facets of their lives (Cruz & Higginbottom, 2013). Therefore, focused ethnography was relevant to the objectives of this study, as I wanted to understand how society presented barriers to and/or facilitated access to oral health care for d/Deaf persons.

Lastly, one of the goals of this study was to explore the potential solutions to improve access to oral health care for the Anglophone d/Deaf community. These goals were consistent with the expected outcomes of focused ethnography, which is to produce relevant and context-specific knowledge for the development of health care services (Higginbottom, 2006).

3.5. Data Collection

3.5.1. Methods of data generation

The use of multiple sources of data is characteristic of ethnography in order to develop an understanding of the social context within which people live and interact (Chan, 2014). Accordingly, I collected two sources of data: semi-structured interviews and participant observation. In contrast to traditional ethnography, where participant observation is the primary source of data, interviews are the main source of data in focused ethnography (Roper & Shapira, 2000), thus semi-structured interviews were my main source of data.

3.5.2. Sampling

I adopted a maximum variation sampling technique, a useful approach to maximize the diversity within the sample (Patton, 1990). According to Patton (1990), maximum variation "aims at capturing and describing the central themes or principal outcomes that cut across a great deal of participant or program variation." Young & Hunt (2011) recommended that any research with d/Deaf persons "must fundamentally recognize the implications of the diversity of the population for the design, practice and validity of social care research" (p. iii). It was therefore pertinent to use maximum variation sampling to take into account the socio-cultural diversity within the d/Deaf population.

From one perspective, to maximize the variation in the sample, it could have been ideal to expressly include culturally Deaf persons as well as those who side with Oralism. However, given the fluid, and intersectional nature of identities within the d/Deaf community, it was difficult to make this distinction during recruitment. This is because, even though, theoretically-speaking, there are two groups of identities within the d/Deaf community (i.e., Deaf and deaf), yet, in practical terms, these identities are not simply dichotomous. Many d/Deaf persons affiliate with both identities at varying degrees depending on their personal choice and context. Therefore, to increase the variation in the sample, I recruited participants from different socioeconomic backgrounds (levels of education, type of dental insurance, family income, and employment status) while staying attentive to issue of identity in my analysis.

In this study, I included adult d/Deaf persons (aged between 18 and 65 years), having ASL as the primary mode of communication. I particularly focused on the adult d/Deaf population since, as compared to d/Deaf children, there is a dearth of oral health literature regarding this population. I selected participants who use ASL as the primary mode of communication since including d/Deaf persons who mainly communicate through speech and lip-reading inherently compromised the communication challenges which I was seeking to address. Further, in addition to participants with dental experiences, I also included persons with no previous dental experience, to specifically explore the reasons why they did not visit a dentist. Lastly, I did not include persons with intellectual disabilities since they might have not been able to express or remember their experiences completely.

3.5.3. Recruitment

Recruiting participants was a challenging and lengthy process, requiring multiple recruitment strategies. Initially, I advertised the study by placing flyers at various locations throughout the MAB-Mackay Rehabilitation Centre. Further, I requested members of the advisory committee to spread the word amongst relevant personal and professional contacts. Neither of these strategies provided potential participants. Members of the advisory committee suggested I reword the flyer into more Basic English given the low English literacy in the community; the committee also advised that I advertise the research through Facebook. According to the committee, Facebook was one of the main platforms which members of the d/Deaf community used to regularly communicate with each other. I thus re-worded the flyer and also posted it on the popular "Montreal Deaf ASL Community" Facebook page.

Following this new strategy, I was able to recruit two participants. Returning for advice to the advisory committee, they suggested producing a video in ASL to post on Facebook. With help a community member, we made a YouTube video with her signing the recruitment script in ASL (e.g., the purpose of the study, nature of participation [45-60 minute interview]). I then posted the video on Facebook. This strategy produced a number of email inquiries and Facebook messages from people who were interested in participating. If the potential participants met the inclusion criteria, I requested them to propose a suitable date and time to organize individual interviews.

In total, I recruited 11 participants for semi-structured interviews, after which I stopped interviewing since I obtained 'data saturation.' Data saturation is a point where additional data would not improve the understanding of the phenomenon under study, and therefore result in redundancies (Russell & Gregory, 2003). According to Strauss (1967, p. 65) "when no new information is forthcoming you have reached saturation point." After conducting and analyzing the first seven interviews, I noticed the following two interviews did not reveal any new insights. Therefore, to ensure that I have reached data saturation, I conducted two further interviews, which also did not raise additional issues.

3.5.4. Interviews

I designed a semi-structured interview guide (Appendix A) based on the suggestions of the advisory committee, and using the conceptual framework I developed for this study discussed above. The interview guide was further modified throughout the process of data collection to cover a range of issues that participants raised during the interviews. In addition to seeking sociodemographic information (Appendix B), the interview guide had five main sections covering the following subjects: finding a dentist; making appointments; perceptions regarding ASL interpretation; communication with the dentists and staff; and, finally, recommendations to improve access to oral health care.

I initiated the interview with the following open-ended question: “Could you please describe your last dental problem and how you managed it?” When participants started to describe a particular event related to the topic, I asked more detailed questions to better understand the different aspects of that event, covering the subjects from the interview guide. In particular, I first asked that in an event in which they required a dentist, how they managed to find one. I then asked questions about the ways they made, or preferred to make appointments. I then conducted a discussion on the topic of obtaining ASL interpretation services, and the professional caliber of interpreters. Following, I asked various questions regarding communication with the dentists and staff. Lastly, I invited them to propose recommendations on ways to improve their access to oral health care in Montreal.

All interviews were conducted in ASL with the help of a professional interpreter who interpreted spoken English into ASL and vice versa. Interviews lasted approximately 30-45 minutes, and with permissions of both participants and interpreters, were audio-recorded. A research assistant then transcribed all interviews verbatim. In total, I interviewed 11 participants between March and May 2015. Interviews were conducted at locations according to the convenience of the participants. Accordingly, four interviews were conducted, in-person, at the MAB-Mackay Centre, while seven were completed via Skype as it was more convenient for these participants than face-to-face interviews. The professional interpreter was present with me during both Skype and in-person interviews.

3.5.5. Participant Observation

I used participant observation to explore the community life of the Anglophone d/Deaf population in Montreal. I was particularly interested in learning how persons who are d/Deaf communicated with each other and with hearing persons. In contrast to traditional ethnography, where intense fieldwork is required over an extended period of time, focused ethnography includes intermittent and purposeful field visits. Accordingly, I spent approximately 50 hours between September 2014 and March 2015 conducting participant observation at a number of social and educational activities of the Anglophone d/Deaf community in Montreal.

During initial meetings, members of the advisory committee suggested that I learn basic ASL to communicate with d/Deaf persons in ASL to help build rapport within the community. Accordingly, I enrolled in two ASL courses, namely: ‘ASL 101’ (30 hours) and ‘ASL Health Care Focus’ (8 hours). The ASL 101 course, offered by the MAB-Mackay Centre, helped me learn basic ASL signs, finger spelling, and simple greetings. The course was also useful for learning about various facets of the d/Deaf community, including the origins, and features of the Deaf culture. At the ASL Health Care Focus course I learned signs that are commonly used in health care settings (e.g., “pain”, “fever”). Further, I was able to understand, through the various case-scenarios presented during class, the sort of experiences d/Deaf persons might commonly have in health care settings. Both these courses prepared me to interact with d/Deaf persons at a basic level, which helped me tremendously during subsequent participant observation activities.

In addition to attending the ASL courses, I conducted participant observations at a social gathering popular amongst the Anglophone d/Deaf community, namely the ‘ASL Social Night.’ ASL Social Night was a monthly gathering organized by the Seeing Voices Montreal. The purpose of this activity was to facilitate social interaction between d/Deaf and hearing individuals. It was an opportunity for hearing persons learning ASL to practice their signing skills. Thus, the context of this meeting provided an opportunity to observe the spontaneous interactions between d/Deaf and hearing persons that was congruent with my goals of participant observation. I felt welcomed by both the d/Deaf and hearing persons as well as members of the SVM.

According to Patton (2009), participant observation combines both observing and informal interviewing. In my visits to the ASL Social Night, I observed d/Deaf persons’ interactions with hearing persons and informally talked to them about their experiences of visiting a dentist. I asked open-ended questions about the experiences they had had communicating with the dentists, making appointments, and hiring interpreters. After conducting participant observation, I recorded my observations by writing ‘field notes.’ According to Montgomery and Bailey (2007, p. 67), “field notes are commonly defined as written records of observational data produced by fieldwork.”

3.6. Data Analysis

Data analysis constituted analyzing field notes and interview transcripts. It was an iterative, cyclic and self-reflective process (Higginbottom et al., 2013), which began immediately after I wrote my first field note. The ‘iterative’ nature of analysis required me to continuously revisit the preliminary data, while I continued collecting further data (Bradley, Curry, & Devers, 2007; Chan, 2014). In this way, I was able to evaluate whether the emerging findings were supportive, or contrary, to the preliminary evidence (Chan, 2014). I analyzed data in three different analytical levels, namely: ‘within-case,’ ‘across-case,’ (Ayres, Kavanaugh, & Knafl, 2003) and ‘ethnographic’ (Roper & Shapira, 2000). This analysis was not a linear process, meaning that I moved back and forth among the different levels (Chan, 2014).

According to Ayres and colleagues (2003), understanding data from an individual interview - or ‘case’ - in its own context (within-case) and “developing a synthesis that captured the essence or variation of experience across individuals” (across-case) (pp. 881-882), helps enrich the interpretation of findings. Further, as Chan (2014) suggested, this strategy also prevents “the tendency of some qualitative research to decontextualize codes or themes from individual accounts and produces only a list of themes” (pg. 67-68). This strategy, as Ayers and colleagues (2003) recommended, helps “distinguish between information relevant to all participants and those aspects of the experience that are exclusive to particular informants” (p. 871).

To conduct the within-case analysis, I first imported the interview transcripts into QDA Miner Lite v.1.4.1. Software. I then performed an inductive thematic analysis of data related to participants’ experiences of accessing oral health care in Montreal. According to Braun and Clarke (2006), “thematic analysis is a method for identifying, analyzing and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail” (p. 79).

Benner (1994) noted that the goal of thematic analysis is to find ‘meaningful patterns’ within data, rather than looking for repeatedly used words or phrases. As Braun and Clarke (2006) explained, during thematic analysis, the researcher assigns a ‘code’ to the relevant segments of the text, reflecting a particular meaning in context of the research question. Accordingly, I first read each transcript line by line, and simultaneously coded different ‘units of meaning’ within the text. For example, since many participants felt frustrated with being dependent on their family members to make appointments, I coded this phenomenon as “frustration with dependence on family.” Following this, I wrote a narrative of each case that included socio-demographic description of the participant along with the story about his or her oral health care pathways.

Across-case analysis involved comparison of participants’ stories regarding each theme emerging from the within-case level. During the across-case analysis, I first analyzed each case narrative, with the specific purpose of recording the similarities and differences amongst the experiences of participants. Using Microsoft Word, I drew tables, representing each theme, and listed the names of all participants. I then put a check mark in front of each participant’s name whose experiences, regarding any particular theme, varied from the majority of participants. This strategy helped me better locate participants with a different experience, following which I re-read their case narratives to understand the contextual reasons behind their unique experiences.

The third level of analysis consisted of an ethnographic analysis. At this stage, I expanded the analysis to be more interpretive and theoretical in nature. In addition to the findings from the first two phases of analysis, I used data from participant observation recorded in field notes, findings from the literature review, and principles of critical theory of disability, the theoretical orientation of the study, to interpret the findings. To do so, I first produced a written report of findings revealed from the first two phases of analysis. Subsequently, while reading a particular section in the report, I cross-checked my field notes to specifically understand how these findings were pertinent to the context of Anglophone d/Deaf community in Montreal, and to the practice of dentistry. For example, through my observations at ASL classes and social events, I was able to understand the context of participants’ experiences related to communication with the dentists. Further, participant observation also helped me understand the social issues of the Anglophone d/Deaf community in Montreal and the ways they integrated in the society; this was beneficial for me to understand how the challenges of social issues of participants also extended to the context of oral health care.

In addition to the participant observation data, I drew links among findings to literature pertaining to the everyday lives of d/Deaf persons and their experiences regarding access to general and oral health care. For instance, one of the findings was that d/Deaf persons, due to their low levels of English literacy, found it difficult to communicate with dentists through writing. It has been repeatedly reported in the literature that d/Deaf persons have low levels of literacy and this has led to difficulties writing in English with health care practitioners (Emond et al., 2015; Harmer, 1999; Kuenburg et al., 2016; Zazove et al., 1993). I was thus able to interpret how everyday challenges of d/Deaf persons also extended to the area of access to oral health care.

Finally, I interpreted the findings through the theoretical lens of 'critical theory of disability.' At this stage, I re-read the report of findings specifically looking at how the society within which the participants lived presented barriers on their pathways to oral health care. For example, one of the participants mentioned that even though he insisted his dentists remove his mask while talking to him so he could read his lips, the dentists continued wearing the mask. The theoretical lens helped orient me to understand that it was not the participant's disability but the lack of awareness by the dentists regarding realities of d/Deafness that presented challenges. This approach helped me explore such instances in the data, thereby enabling me to reveal the shortcomings of society in accommodating the oral health care access of d/Deaf persons. Also, it is worthy to note that although the framework of 'barriers' and 'facilitators' forces two categories, they were not always simply dichotomous. In reality, participants' experiences of accessing oral health care services was a continuum from restrictive to enabling factors. I therefore used critical theory to address the 'restrictive' end of this continuum, and brought the 'enabling' end into the discussion of solutions.

3.7. Ethical Considerations

I obtained ethical approval for this study from the Centre for Interdisciplinary Research of Greater Montreal (CRIR) ethics board, which is affiliated with the McGill University Research Ethics Board (REB). I required a CRIR ethics approval since the study was partially conducted in, and involved recruitment from, one of the CRIR institutions' site, namely the MAB-Mackay Rehabilitation Centre. At the beginning of each interview, participants signed a consent form, available in both English and French (Appendix C, D). The consent forms consisted of a brief description of the project, as well as the nature of participants' participation. The interpreters also signed this consent form specifically giving their approval to be audio-recorded. I reassured the participants that they had the right to withdraw from the study at any time. I also reiterated that they had right to not respond to questions and/or issues that made them feel uncomfortable. For participation observation, I did not obtain a written consent, however I informed all participants verbally that I am a researcher and briefly described my research project. According to the Tri-Council Policy Statement (2010), observations which do not constitute a staged environment for the purposes of research and ensures the anonymity of participants are considered minimal risk, and qualifies for exemption of written consent from the participants. To protect the participants' confidentiality, I used pseudonyms to label the interview transcripts and field notes. All data is stored in password-protected files in the computers of the research team at the Division of Oral Health & Society of the Faculty of Dentistry, McGill University. In accordance with McGill standards, all data will be destroyed seven years after the publication of results.

3.8. Methodological Rigour

I took several measures to ensure the scientific rigour in this study, mainly following the evaluative criteria of Lincoln and Guba. According to Lincoln and Guba (1985), the 'trustworthiness' of results is important to evaluate the worth of a qualitative study. There are various ways in which researchers can enhance the trustworthiness of the research findings.

3.8.1 Credibility

Credibility represents the truth value of the research, meaning the extent to which the results of a study are believable. Lincoln and Guba (1985) suggested that prolonged engagement in the field is one of the most important determinants of the credibility of a study. In the present study, I spent approximately 50 hours, over a period of one year, in the field, establishing partnerships and conducting participant observation. In addition to prolonged engagement in the field, I maintained credibility through persistently observing various elements and characteristics relevant to the phenomenon under study. For example, as described earlier, one of the goals of participant observation was to specifically observe how d/Deaf persons communicated with hearing individuals. Accordingly, during the participant observations sessions, I actively kept a keen eye on such interactions. Lincoln and Guba (1985) state that “if prolonged engagement provides scope, persistent observation provides depth” (p. 304). Therefore, I was able to both cover a wide range of elements pertinent to the research question, as well as study them in-depth.

In order to further enhance the credibility of the results, I conducted peer debriefing sessions with both my supervisors who had different academic backgrounds, dentistry and anthropology. After every interview and observation session, I conducted a discussion with my supervisors to seek their feedback on my interpretation of the data, which helped me challenge and validate my interpretations. Further peer debriefing helped me identify important aspects in the results which I might have overlooked without the feedback of my supervisors. Triangulation, the strategy of collecting data through various resources is another method to ensure the credibility of findings (Patton, 1999). In this study, I achieved triangulation by collecting data through both formal and informal interviews with d/Deaf persons, as well as by conducting participant observation.

3.8.2. Transferability

Transferability is another approach that helps enhance the trustworthiness of a study. According to Lincoln and Guba (1985) “describing a phenomenon in sufficient detail one can begin to evaluate the extent to which the conclusions drawn are transferable to other times, settings, situations, and people” (p. 306). A researcher can ensure the transferability of the findings by providing a ‘thick description.’ Holloway (1997) stated that “thick description refers to the detailed account of field experiences in which the researcher makes explicit the patterns of cultural and social relationships and puts them in context” (p. 154). Accordingly, I endeavored to enhance the clarity of my findings by providing a thick description of the cases (individual stories), the settings, the context, and the results.

3.8.3. Reflexivity: My role as a researcher

According to Malterud (2001) “a researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions” (pp. 483-484). Reflexivity, as Higginbottom and colleagues (2013) described, is an approach that takes into account how a researcher's a priori assumptions contributed to the inception of a study and how it shaped the research process. Therefore, it is important to explain my motivations and professional experiences that inspired me to conduct this study. I graduated as a dentist in 2010 from the University of Karachi in Pakistan, following which I pursued a one-year general practice residency program. During the residency, I felt compelled to establish strong working relationships with patients, through which I realized the value of effective communication in strengthening such relationships. Importantly, it was also during this training that I first interacted with a d/Deaf person who came to me to have his teeth cleaned. With no previous experiences interacting with d/Deaf persons, and no formal training in dental school on how to communicate with a d/Deaf patient, I found it challenging to communicate with the patient. Moreover, I felt disappointed with not being able to establish an authentic 'dentist-patient' relationship with the patient, which I greatly valued as part of my dental practice.

I came to Canada in 2012 to pursue a Masters of Dental Sciences at McGill University, under the supervision of professors using qualitative research to working on access to dental care for underserved populations. Having worked in a hospital in Karachi, Pakistan where I mostly provided dental care to low-income populations, I was sensitized to the issues of such populations. During my early months in graduate school I met a colleague who was working with persons who use wheelchairs. Listening to her experiences, I felt inspired to work with persons with disabilities. The challenges that I faced while working with the d/Deaf patient mentioned above motivated me to work with the d/Deaf population. In particular, I was excited about the novelty of the idea since this is a severely under-researched area in dentistry. Further, I was intrigued with the opportunity to serve and advocate for a community that has a long-standing history of stigma and discrimination.

In this study, I promoted reflexivity by maintaining a reflexive journal constituting my personal reflections regarding the phenomenon under study and the process of research. For example, I initially viewed the d/Deaf population strictly through the lens of the medical model; as persons with a physical deficit who needed cure. However, as I started working on the project, reading the literature, and conducting discussions with the advisory committee, my perceptions regarding the realities of the d/Deaf population began to change. I realized that social issues of the d/Deaf population were explicitly a product of a society that did not accommodate basic needs of the persons, restricting them to function as equal to the hearing persons. Further, it was also fascinating to learn about the Deaf culture. I was surprised to learn that culturally Deaf persons did not consider their d/Deafness as a disability, but rather a cultural and linguistic difference. This process of ‘unlearning’ led me choose the theoretical orientation for the study and motivated me to include community members as research partners.

Chapter 4: Results

This chapter presents the findings of this research study. In the following pages, I begin with a description of the participants, then present the data on participants' experiences and perceptions regarding challenges which they experienced on their pathways to oral health care in Montreal, and the solutions they proposed to overcome them. It is important to note that the process of oral health care was not linear, contrary to how it is described below for the purpose of clarity. In reality, the oral health care pathway of d/Deaf persons represents an iterative process, where d/Deaf persons can move back and forth between different stages according to their individual circumstances. For example, if a person faces difficulties in communicating with a dentist (stage 5), he could exit the pathway, and restart the search for a new dentist (stage 1), all over again. However, given an ideal situation, where a d/Deaf person traverses from the beginning to the end of the oral health care pathway, he or she may go through the six stages, as described below.

4.1. Description of the participants

The participants in this study included 11 d/Deaf persons, seven men and four women, who used American Sign Language (ASL) as their preferred mode of communication. Participants' ages ranged between 21 and 56 years (with 37.6 years as the mean age). Of the 11 participants, four worked full time, three were full-time university students, and four were unemployed; one was on social assistance, one was a homemaker, one was looking for employment, and one was retired. Nine participants had private dental insurance, of which five had family insurance, three had employment insurance; a public insurance programme covered an additional participant. Two participants did not have dental insurance: one paid 'out-of-pocket' for oral health care, while the other had no means to cover the costs of care. In terms of education, six participants graduated from high school, two from college, and four had university degrees. Lastly, all participants lived with their family members; three with a spouse, seven with parents, and one with a sibling.

Table 2. Description of the participants

Sociodemographic characteristics	*N*
Gender	
Male Female	7 4
Age range	
18-29 30-49 50-65	3 6 2
Annual family income	
<30,000$ 30,000-50,000$ >50,000$	3 3 5
Dental Insurance	
Insured Public Private Non-insured	9 *1* *8* 2
Employment	
Employed Unemployed	5 6
Education	
High school or under College degree University degree	5 2 4

4.2. Answering the research question

To answer the research question, “How do persons who are d/Deaf experience access to oral health care in Montreal?” I requested participants to describe their individual oral health care pathways, including the barriers that they faced when seeking care. The following passages provide a description of participants’ experiences during each stage of their oral health care pathway.

4.2.1. Stage 1: Choosing a dentist

Participants used various methods to find a dentist, the most common of which was a referral through family members or friends. When either choosing, or deciding to continue visiting a particular dentist, participants considered two main factors: the costs of dental services; and the quality of communication with the dentist.

Methods used for finding a dentist

At the time of interview, all but two participants had a regular dentist. Of the two who did not have a regular dentist, one was looking for a dentist, while one did not perceive a need to consult a dentist in the near future. Participants described various methods that they used to find a dentist. These ranged from referral through family members or friends (N=8), to searching the Internet (N=1), and to exploring the neighborhood on foot (N=1). Lastly, one participant requested his dental insurance company to suggest a dentist.

Financial considerations

When choosing a dentist, one of the main factors that participants considered was the cost of dental services. Accordingly, a few participants pointed out that when choosing a dentist they first compared the rates at which various dentists offered services, subsequently choosing the one who proposed the cheapest rates. Given the high costs of dental services in general, this situation might not be specific to d/Deaf persons. However, as pointed out in the literature review section, d/Deaf persons generally have both high unemployment rates and/or work in low-paying professions. Therefore, both the high costs of dental care and the low socioeconomic status of d/Deaf persons can raise apprehension about affording the cost of care amongst d/Deaf persons, as was the case with many participants in this study. Commenting on these issues, a low-income factory worker stated:

> Well, I'm not searching for a dentist right now but if I was, then finances, the price difference, you know more expensive less expensive, I don't know what the cost differences are but that would be one factor.

As discussed in the next section, quality of communication was the most important factor for participants when either choosing or continuing to visit a particular dentist. However one participant mentioned that he was willing to compromise on the quality of communication, given the dentist offered services at cheaper rates. As illustrated in the excerpt below, one participant, who was on social assistance, mentioned that the quality of communication with his current dentist was poor. However, he preferred to visit the same dentist since the latter provided services at 'cheap' rates:

> I had a feeling that it was time to change to another place… but the problem with that is that it's expensive [other dental offices]. The place that I have been going to is pretty good and cheap… so that's the reason why I have been going there for a while. The cleaning is $90 and I'm assuming other places is $130 and more… so $90 is cheap.

Overall, the concerns of participants reflects the inadequacy of the oral health care delivery system in Canada in providing care to low-income patients (CAHS, 2014). In Canada, dental care is mostly funded privately; people generally either pay out of their own pockets, or through public (welfare recipients insurance) or private dental insurance plans (CAHS, 2014). In addition to those with low income, these issues may affect those who are unemployed, and have no dental insurance. In my sample, there was a 59-year-old man in a similar situation: he was seeking employment but had not yet applied for social assistance. Keen to be able to visit his dentist once again, he mentioned:

> I have no benefits. I have no pension, nothing here. I can't afford it [dental care]. Well, I am looking for a full-time job and when I do I will be able to go back to the dentist again.

Quality of communication

Participants mentioned that prior to choosing a dentist, they were already apprehensive about the issue of communication. As mentioned above in Chapter 2, communication with hearing persons is an on-going challenge for the d/Deaf community. Accordingly, a few participants mentioned that they would prefer consulting a dentist who was d/Deaf. Yet, except one participant, the rest did not know of any d/Deaf dentists in Montreal. “I was just thinking that if there was a d/Deaf person studying dentistry… I think it would be great… I have never heard of any d/Deaf dentist,” stated a 26-year-old participant, who was also an active member within the local d/Deaf community. Elaborating further that how a d/Deaf dentist could help overcome the anticipated communication challenges, she mentioned:

> It will be wonderful if they [the dentists] are d/Deaf… because I feel the communication would be great! I don’t know if there are many d/Deaf dentists at all... so that would be difficult. I have a lot of friends who are hearing, and a lot of them want to learn American Sign Language so I teach them a little bit… but there wouldn’t be a need to teach anyone anything if they already knew it, right? If a dentist was d/Deaf already, I mean...

A 40-year-old woman, who was active within local d/Deaf organizations mentioned that she knew a d/Deaf dentist in Montreal, whom she met at a few d/Deaf community events. Elaborating further, she mentioned that this d/Deaf dentist represented the Montreal d/Deaf community within the local dental network. However, since this dentist was mostly proficient in LSQ and French, it limited his accessibility for d/Deaf ASL users in Montreal.

The important point to take away from these participants' comments is that simply having a ‘d/Deaf dentist’ does not necessarily ensure effective communication. Linguistic barriers affect d/Deaf persons in a similar way as they may affect the hearing people in Montreal. For instance, the barriers that an Anglophone hearing person might experience while consulting a Francophone dentist are comparable to those that an Anglophone d/Deaf person faces when communicating with a Francophone d/Deaf dentist. The d/Deaf ASL users however experience additional communication barriers due to both their hearing loss as well as the barriers that manifest as part of the larger societal context of living in a city with a first language (French) different from their own (English).

Although ideal, the possibility of having a dentist in Montreal who is both d/Deaf and proficient with ASL is rare. The next 'best thing,' according to participants, is a hearing dentist who has basic signing skills of ASL; however, there are only a limited number of hearing persons in Montreal who are proficient in ASL. Acknowledging these realities, participants emphasized that when choosing a dentist, they looked for a dentist who would provide an ASL interpreter. "I want to know if I have to pay for the interpreter or it's covered or it's free. All those things are factors I would keep in mind. Does a dentist typically pay for an interpreter, or does insurance partly pay for it? - those are kind of things that are important for me", stated a 39-year-old participant discussing her preferences. Issues related to the affordability and availability of such interpreters are further discussed below (see Section Stage 3).

4.2.2. Stage 2: Making appointments

The majority of participants expressed frustrations with making new appointments, and to responding to telephone messages regarding recall appointments. Participants mentioned that even though talking on the telephone was impossible for them, the office staff only offered to contact them via telephone; consequently, they had to depend on family members to make appointments. In the words of a 26-year-old woman:

> When it comes to contacting, not only dentists but anyone really, there are only so many ways that it can be done, and using a phone in a conventional sense is not technically possible. My mom is the one who will make the appointments for me, no matter what the appointment is.

As highlighted in Chapter 2, the advent of technologies such as smart phones and computers has increasingly made it easier for d/Deaf persons to communicate independently. Accordingly, most participants mentioned that a convenient way to make appointments was either through text or email. Although a few participants tried to sensitize the dental staff about these issues, these staff continued using telephones. A participant who felt frustrated being dependent on his mother mentioned:

> I don't want to be dependent on my mother… I keep telling them [the staff] "Please email me" and I've said that a number of times… but they respond to that by saying that they don't use email…I then ask "Can you please text me?"… So they say that they can't do that as well. Then I say "Fine! Call my mom"… they have their voice conversations…

Another participant stated:

> I want to be able to text and make an appointment. I mean, hearing people are able to pick up the phone and make an appointment. Why can't I have the same access? I want to be able to text someone and make an appointment that way. It seems like a lot of offices don't… "Oh no, we don't allow that"… So how do you expect me to do this? It's the most reliable way for me to do so!

As the participants described, it was the culture of dental offices to contact patients regarding appointments over telephones. This situation may reflect a lack of awareness by hearing persons regarding the needs of d/Deaf persons in general. As noted in the literature review section, d/Deaf persons only constitute a small portion of the general population. Therefore, as pointed out by the participants, the lack of awareness by dental staff might be linked to the limited frequency with which the staff met d/Deaf persons in their everyday lives.

Telecommunication Device for the Deaf (TDD) is another way d/Deaf persons can make appointments on their own. TDD is a telephone-based device that allows d/Deaf persons to communicate over regular telephone with hearing people (Penttinen, 2015). However, except for one, none of the participants preferred using TDD, referring to it as an "old-fashioned" and "time-consuming" technology. "TDD is an old system… I don't see many people using TDD anymore," stated a college student.

According to the participants, the main issue with TDD was that it restricted them to be home as it was heavy to carry outside. "You can't bring it out with you… to use the TDD you have to be home, you can't take the TDD outside with you," said a 26-year-old woman. The same participant explained how the limited use of TDD may exacerbate problems in emergency situations: "If I am out somewhere…. Not specific with dentists… but for example, if I have a car accident and I need to contact emergency services… do you want me to rush all the way home first? That doesn't make sense!"

The important point to understand from the participants' comments is that there is a mismatch between the resources being offered and the preference of participants. Although TDD could allow participants to make appointments independently, they do not prefer to use it and have other suggestions – email and texting – that better meet their needs. Frustrated with these issues, one participant mentioned that in order to avoid further feelings of disappointment, he would rather visit the dental office in-person to make appointments. Expressing his feelings, he stated:

> If I wanted to make an appointment, I wouldn't want to rely on my parents because I'm an independent person. Honestly since it's so close [the dental office] I would just walk over and let them know that I wanted an appointment. They don't use email so I would just go in person.

Importantly, some participants also pointed out that texting, emailing or using TDD may not be possible for persons with low levels of English literacy, further restricting them to make appointments independently, or having them resort to a tedious method, such as visiting in-person. Speaking about these issues, an active member of a local d/Deaf organization, well-versed with the issues of the community, explained:

> There are some d/Deaf folks who have a high level of literacy, and can perhaps email or use the TDD services to book an appointment…But then there is another group of d/Deaf folks whose literacy level may not be as high… and I have spoken to some of them… they go to the office in person to make an appointment for next year or a yearly appointment.

Although, visiting the dental office to make appointments could help d/Deaf persons overcome the challenges related to telephone communication, this mode of communication has its own limitations. For instance, it may not be feasible and convenient for persons who live far away from the office, or those with physical disabilities.

According to participants, the 'ideal way' to make appointments would be through the Video Relay Services (VRS). VRS, provided by the Canadian Radio-television and Telecommunications Commission (CRTC) , is a telecommunication service which enables sign language users to communicate with hearing persons over the telephone (CRTC, 2015). The sign language user connects to a VRS operator, who then places a phone call to the other party and relays the conversation from sign language to voice, and vice-versa (CRTC, 2015). According to the Canadian Administrator of VRS, VRS will be launched in Canada in the fall of 2016 (CRTC, 2015).

Participants pointed out that the main reason they would prefer using VRS was because, unlike TDD, it would enable them to communicate in their first language (i.e., ASL). "If you are aware, the TDD is such a long and torturous way to communicate in any way… VRS will allow one to use their first language to communicate," stated one participant. Additionally, in comparison to TDD, VRS does not require a person to be at home as it is compatible with smart phones. With the operationalization of this service, participants felt hopeful about overcoming the challenges they currently face with making appointments. Speaking about the benefits of VRS, this 40-year-old participant also mentioned:

> I don't like TDD as you have to stay home, you can't go out… with VRS you can use Smartphone, and you can be anywhere and make an appointment that way. In the same way that hearing people can make the same appointment, I'm not going to go home and stay there just to make an appointment, it doesn't make sense.

4.2.3. Stage 3: Hiring an interpreter

According to the participants, 'ideally' the next step in their oral health care pathways was to book an interpreter who could help with communication in the dental office; however, only one participant was able to do so. As described in Chapter 2, following the Eldridge v. British Columbia decision of the Supreme Court of Canada, d/Deaf persons are entitled to free interpretation services when using any services covered under the Canada Health Act (Parise, 1999). Oral health care services, however, does not constitute this Act. Consequently, d/Deaf persons have to pay for interpretation services for their dental appointments themselves.

In this study, participants pointed out that, prior to visiting a dentist, they were unaware that they were not entitled to free interpretation services for dental appointments. As a result, many participants expected that an interpreter would be present when they visited their dentists for the first time. According to the participants, this misconception stemmed from their experiences with general health care, as they always had access to an interpreter for the doctor's appointment.

> At the hospital if I say "I need an interpreter" …they would make a call, and an interpreter will show up very quickly. In my experience it has been very fast! It tends not to matter whether it's an appointment which is scheduled beforehand or is a last minute request …there is usually an interpreter as soon as possible (59-year-old man)

Further, a few participants mentioned that, following confirmation of the dentist's appointment, they requested an interpreter through a local interpretation agency. According to these participants, they contacted the agency as they were used to doing the same prior to the doctor's appointment. However, as noted earlier, since d/Deaf persons are not entitled to receive free interpretation services for dental appointments, the interpretation agency either did not respond or denied their request. "I contacted an interpreting agency… there is an online form that one has to fill to make a request… so I had put in all the information in terms of when I needed an interpreter and all that… I didn't receive an answer from them," stated a 40-year-old man.

Elaborating further, he mentioned:

> Normally for a family doctor they [interpretation agency] will answer by saying that an interpreter will be provided. My understanding is that dentistry falls into a different category of services… and they [interpretation agency] can't cover that… or their mandate doesn't cover the dentists' appointment. That's why no interpreter was provided.

The belief that d/Deaf persons were entitled to free interpretation services for dental appointments was common across several interviews. For example, a factory worker, who was yet to consult a dentist in Montreal, stated:

> If I need to go to the dentist, I would book an interpreter through a local interpreting agency. Typically they help us book an interpreter, so I would contact them and make sure I have an interpreter for the dentist.

An immigrant from the United States mentioned that since she had not visited a dentist in Canada so far, she did not know if she was entitled to free interpretation services. During her interview, she asked me if she could have an interpreter for dental appointments:

> I haven't been to the dentist here in Canada yet. I may soon. Do you know if we [the d/Deaf persons] are able to book interpreters for the dentists here in Canada?

Later she added:

> I want to know if I have to pay for the interpreter or it's covered or it's free. All those things are factors I would keep in mind. Does a dentist typically pay for an interpreter, or does insurance partly pay for it? Those are kind of things that are important for me

Further, except one, all participants mentioned that they could not afford to pay for interpretation services. Given these issues, participants expressed that they wished their dentists themselves could arrange the interpreters' appointments as well as cover their costs. Expressing her feelings, one participant, who was a member of the organizing committee of various social events of the d/Deaf community in Montreal, mentioned:

> An interpreter would be most effective [for communication] but then that's expensive… and my mom doesn't want to pay for an interpreter. I mean, that's just sort of a life thing we go through at my family. I don't know if the dentist would hire an interpreter. I don't know if they would entertain that possibility. So that makes it hard, that's what I mean.

Elaborating further, she stated:

> I wish that the dentists themselves would call an interpreter for their appointment with the d/Deaf patient. I wish they would do it before the appointment and not you know… last minute. Of course if it is a last minute emergency then that is an exception.

Another participant, a 21-year-old man who mentioned that he had visited dentists over twenty times during his life, stated:

> The dentists don't hire interpreters… they don't have their own interpreters… If the d/Deaf patient needs an interpreter but the dentist refuses to pay then the patient has to pay himself… the dentists will tell that they don't have an option… the problem is that they [the dentists] are not aware that they have d/Deaf patients sometimes.

Another issue some participants pointed out was that they did not understand the process of hiring an interpreter, with many referring to it as "a complicated process." "I don't know what that process looks like… how do you locate an interpreter? How do you book an interpreter? How do you arrange the cost? I don't know what that looks like… I'm not sure what that involves?" stated a 26-year-old participant. Interpreters in Montreal have a policy of charging a minimum of two hours, at an average of $55 per hour. Not knowing the precise amount of time their dental appointments could take, many participants were unsure of the durations for which they should hire an interpreter. Sharing her apprehensions about these issues, a university student, who was yet to hire an interpreter for her dental appointment, mentioned:

> For my dental appointment, it would depend on a lot of things. I don't know how long will it take for me to be seen in a dental office. So I don't know how that would work in terms of getting an interpreter.

While d/Deaf persons are not entitled to receive free interpretation services for oral health care, one participant mentioned some exceptions she gleaned from a conversation with a representative of the local interpretation agency. According to this participant, these exceptions included: first time consultation with the dentists; cases requiring extensive treatment planning (e.g., orthodontic cases); complex procedures (e.g., surgery); and treatment provided at the hospital. Sharing what she had learned, she stated:

> I had a conversation with them [the interpretation agency] about this before and they said they will supply an interpreter for a first time assessment. If there is a serious surgery, there are also interpretation services that they will provide and for some appointments afterwards. When explaining a treatment plan for example, if that's when that's going to happen in the appointment, then an interpreter will be provided. Or for example, if care can no longer be provided at the dental office and the patient is referred to a hospital then again an interpreter will be provided at the hospital.

To the best of my knowledge, there are no written official resources which could confirm the accuracy of this participant's comments. I personally contacted a representative of the local interpretation agency who confirmed the accuracy of her claims, however. Additionally, since dental treatment provided at the hospital is covered by the RAMQ, which falls under the Canada Health Act, d/Deaf persons are entitled to free interpretation services at the hospital.

An additional issue participants discussed regarding interpreters was a perceived scarcity of qualified ASL interpreters in Montreal; this scarcity adds to the difficulties participants experience during dental appointments. "I feel there aren't enough interpreters. In the LSQ-French community, there are plenty of interpreters… but the ASL-English interpreters aren't very many in Montreal… I can't think but there are maybe 6 to 7 in town," stated a 26-year-old woman. The dearth of ASL interpreters could possibly be due to French being the first language in Montreal, with relatively few English-speaking residents in the city. Speaking of these issues, another participant, who confirmed this situation with her d/Deaf friends living in other large Canadian cities, mentioned:

> My friends who live outside of Montreal in different towns in Canada, they don't experience this [the scarcity of ASL interpreters] there. They have a lot of ASL interpreters where they live, and yet the opposite problem is that there are very few LSQ-French interpreters. For example in Ottawa I don't know how many LSQ-French interpreters there are. But I think they are not many. There are a lot of ASL-English interpreters [in Ottawa]… but for an interpreter in Ottawa to come all the way to Montreal… that's a lot of travel.

4.2.4. Stage 4: Interacting at the reception and the waiting areas

After reaching the dental office, the next stage in the oral health care pathway of participants was to notify the receptionists about their arrival, and then wait to be seen by the dentist. Given the difficulties with hiring an interpreter, most participants visited the dental office with a family member.

Interaction with the receptionist

Participants pointed out that the first time they approached the receptionists, the receptionists 'panicked,' not being aware how to communicate. The receptionists started by speaking as they would do with hearing patients. "It was the first time I had been to that office. I was there with my sister and mom. I think it was the receptionist's first time ever seeing a d/Deaf person because when I approached her, she immediately started talking. I asked my sister to interpret, who told me that the receptionist said that it was the first time she ever conversed with a d/Deaf person," stated one participant. A similar story was that of another participant who visited a dental office near his home to get an appointment for cleaning. Sharing his story about his interaction with the receptionist, he mentioned:

> I remember getting there and seeing the receptionist… She immediately started talking. I politely gestured her to stop and said: "Hello! I'm d/Deaf." But I remember she continued talking and I tried to calm her down and said: "Can we write back and forth?"… So we started writing back and forth.

Two other participants shared similar experiences with the receptionists. Reflecting on their experiences, they mentioned that perhaps the receptionists may have felt overwhelmed interacting with d/Deaf patients, due to their lack of awareness about d/Deaf persons in general. Participants pointed out that this lack of awareness by dental staff might be related to the limited frequency with which the staff met d/Deaf persons in their daily lives. One of them, a 26-year-old woman, stated: "I'm kind of still thinking about the frequency at which hearing people meet d/Deaf people… and how they react to whether it's their first time or whether it's the patient they have known for years."

The other participant, an immigrant from the United Kingdom, expressed that it is important that receptionists are aware of the needs of the d/Deaf persons. He believed that since receptionists are often the first people patients meet in a dental office, positive experiences with them may help reduce patients' anxiety for the rest of the appointment:

> Whenever I go to the dentist I am always a little nervous and so to start off with a receptionist who is friendly and approachable would be great. And it would influence how the rest of the appointment would go. I think some awareness would be great! It's often that a d/Deaf patient approaches a hearing person and everybody becomes uneasy and a little restless and that affects the patient. I think if people sort of treated d/Deaf people just like any other patient that would go a long way. As opposed to being shocked, flabbergasted, and wondering "What am I going to do in this situation" It should be like "Oh you are d/Deaf? Okay, how are we going to do this? Let's try writing back and forth?

Later he added:

> If they had a little bit of signing skill, just the ability to say "Hello! How are you? That would be great! It would put me at ease but it's unreasonable to expect everyone to learn sign language. Recently, my receptionist told me that they are learning ASL…

Waiting areas

The usual way dental assistants notify their patients of their turn is by calling their names out loud. This is obviously not an appropriate way to seek a d/Deaf person's attention. Most participants complained about this practice, not aware when their names were being called. Participants pointed out that one of the reasons the staff communicated in such ways was because they did not know these patients were d/Deaf. It is indeed difficult to tell if a person is d/Deaf simply by his or her physical appearance, which is why d/Deafness is often referred to as an 'invisible disability' (Shohet & Bent, 1998).

The ‘best way’ to overcome these challenges, according to participants, was to notify the dental assistants in advance that they were d/Deaf, subsequently making them aware of their preferred ways of communication. Accordingly, some participants pointed out different ways the staff could notify d/Deaf patients in the waiting areas. For example, a 40-year-old man mentioned that after facing difficulties communicating with the receptionist, he notified her that the best way for the dental assistants to let him know of his turn was as follows:

> I wrote on a piece of paper that don’t call me if I’m not in the room or away from the room… please have them approach me and stand in front of me to make it clear that it’s my turn. That’s what the dental assistant did… she gestured to follow her. For the next appointment dental assistant walked up to me to tell me that it’s my turn.

Another way to seek a d/Deaf patient’s attention is to touch and/or tap them: “Whenever I have gone to the dentist, I have always made it clear to the assistant or receptionist that I am d/Deaf, and I’m in the waiting room… and when it’s my turn, please do not to shout or anything… just let me know by touching and pointing to the office,” stated a university student. Another participant confirmed that he was satisfied with the staffs’ way of tapping on his shoulder to let him know of his turn because “it’s not like they rush up in front of me… they tap me on the shoulder.”

Further, another woman proposed that the d/Deaf persons should “keep an eye” on the patient ahead of them to know when it was their turn: “Sometimes I know who is ahead of me, so that helps too when I see the person who is ahead of me go so I know that I’m next. So I become a little bit more attentive.” Visiting the dentist with an interpreter helps avoid these issues: a 56-year-old man stated: “The interpreter simply hears my name and tells me that it is my turn.”

4.2.5. Stage 5: Meeting the dentist and treatment planning

When participants met the dentists, the dentist inquired regarding their reasons to visit, then conducted an oral examination and proposed a treatment plan. Participants expressed difficulties communicating with the dentists, especially when the dentists explained the treatment plans, which were extensive and required detailed explanations.

Communication with the dentists

Participant felt that the treatment planning stage was the most important stage in their oral health care pathways; at this stage they had the opportunity to understand the sort of dental problems they were facing, and the type of procedures the dentists were going to perform (if any). Thus, according to the participants, the greatest need to communicate with the dentists was at the stage of treatment planning. As highlighted in the literature review section, d/Deaf persons communicate in multiple ways with individual communication preferences, depending on such elements as education and cultural affiliations. In this study, participants communicated with their dentists using through interpreters (either family or professional), lip-reading, writing; and using gestures.

Family members as interpreters

One of the participants hired a professional interpreter; the rest communicated with the dentists through the support of family members who acted as interpreters. “My parents sort of support me with the communication stuff. They have always done that in terms of being interpreters,” stated a 26-year-old university student. Similar stories recurred throughout the study. For instance, one woman, who had previously undergone an orthodontic treatment mentioned: “Well my parents, they are hearing so they were able to communicate for me. We went to the dentist several times together.” Another participant, a local college student mentioned:

> Most of the time my mother and sister are with me and they explain to the dentist what I need. They are not like interpreters but they know sign language and they are able to interpret for me… you know? What the dentist says? But if I imagine going through it myself …I wouldn’t understand… I would need somebody to be there to help with the communication.

Although convenient, most participants described challenges with their family members interpreting during dental appointments: family members were often not able to interpret effectively since they were not trained interpreters, and were not fluent in ASL. Consequently, participants often did not understand the complete treatment plan that the dentist explained. Sharing her experiences, a 40-year-woman mentioned that she faced challenges communicating with her dentist when her mother acted as an interpreter. She stated:

> My mom and I had talked about it before and she was like "Do I need to be there? It will be simple right? They will just take it [the teeth] out? I said "Oh, but you might be there just in case." And what we thought what will be a simple appointment ended up very complicated. There were forms to sign and explanations to do and my mom and I were like "Isn't this just a simple thing?" The dentist explained "Oh no this is a new procedure so therefore we need to ask you all of these questions."

Elaborating further, she explained that since her mother was not able to keep up with the pace of interpretation, she only conveyed the "main points" instead of what the dentist really said, which was frustrating for her:

> It was uncomfortable for me because my mom is not a trained interpreter, so she didn't interpret so much as she was having a conversation with the dentist. She only explained the summary of it to me. My mom and I were both upset; we were like "You should've told us beforehand! Why didn't you let us know beforehand? We could've had an interpreter here and it would've been so much easier and better and more efficient but whatever." So I would've preferred knowing in advance what the appointment will look like in order to be better prepared. Because I would've used an interpreter in that situation but again my mom and I just predicted incorrectly.

Another participant expressed dissatisfaction with her mother and her sister's interpretation during her dental appointments since they were not fluent in ASL:

> My mom and my sister have always kind of acted like interpreters but they don't use American Sign Language vocabulary. They finger spell English words so what I am exposed to is English vocabulary that I am not familiar with and I don't understand the meaning so that's why that has kind of not been effective.

Similarly, one participant who visited a dentist with his spouse for an emergency appointment shared similar experiences. He mentioned that while initially he tried to lip-read the dentist, it became harder for him to pick words off her lips as she spoke quickly to convey enormous amount of information in a short time. "She tried to explain to me some things about the X-ray but that wasn't very clear, and afterwards she started to go more into depth explaining something, and I was missing more and more and more and more." He therefore requested his spouse to interpret for him, which was not effective either; the dentist continued speaking quickly, which led his spouse to only convey the main points. Consequently, he did not wholly understand his treatment plan:

> There was no patience. I remember my spouse just signing, and going and going. And I wanted to interrupt but he said "Oh! The dentist isn't stopping! She is still talking! My spouse is not trained as an interpreter, it's not his profession. So, I mean, it's normal… but all it was doing was making me feel a little worse. I wish I could've asked a bit more questions, had there been an interpreter there, it would've been a different appointment.

As noted earlier, participants expressed difficulties understanding their treatment plans when a family member interpreted. Accordingly, most participants felt that it was best to have a professional interpreter when discussing treatment plans with the dentists. They felt that conversations would be "clearer" and "quicker," compared to when family members interpret. "With an interpreter, things go by very quickly. If there is another person in the waiting room… with God forbid a lot of pain, I don't want them waiting for me to finish my appointment," stated a university student. Another participant stated: "An interpreter would be fast and quick access through interpretation services."

In contrast to those who faced difficulties with their family members interpreting, one 56-year-old participant accompanied by a professional interpreter experienced no difficulties understanding his treatment plan. He stated:

> I went with the interpreter and the information was explained to the both of us. It's better with an interpreter because I understand more clearly with the interpreter.

Direct communication with the dentist

In contrast to communicating with the dentists through either their family members or professional interpreters, participants described various situations where they communicated with the dentists directly. For instance, some participants mentioned that they did not perceive a need to communicate extensively with the dentists for simple procedures (e.g., cleaning) since they were familiar with these "routine procedures," and thus, visited the dentists alone. "For cleaning it's usually something that I decide myself that its time… and I go, they do the cleaning. It's an appointment that I am familiar with," stated a 40-year-old participant. Another participant mentioned that she visited the dentist with her mother only when the appointments were "serious." She stated:

> Sometimes my mom comes and she will interpret. If it’s something quite serious, I will always get my mother to come. If it’s something routine like a cleaning I will go by myself.

When alone, participants communicated with the dentists in different ways, the most common of which were through writing, and using gestures. For instance, one 59-year-old man fluent in English stated that he was comfortable communicating with the dentist through writing. Another 38-year-old participant who had always visited his dentist by himself, had a similar opinion. He stated:

> I feel comfortable with communication… it’s easy for me. My dentist or the assistant would write with me. My dentist knows me… and we are comfortable with each other… so it’s not a problem. He writes the information on paper.

Although a couple of participants routinely wrote, most participants disapproved of this method for detailed explanations during treatment planning, referring to it as a “time-consuming,” and “ineffective” method. A few participants mentioned that since writing was a tedious task, it often left them feeling guilty with making other patients wait for their turns. “If there is another person in the waiting room…I don’t want them waiting for me to finish my appointment,” stated a 26-year-old woman, describing why she did not prefer writing.

In addition, the participants mentioned that dentists usually wrote lengthy passages to describe the treatment plans, instead of short and simple messages, which further added to the total time of communication. Describing why she did not prefer writing with her dentist, a 26-year-old student stated:

> Writing back and forth takes a long time. For example, if I ask a question and the answer is quite long then that it takes a lot of time... It’s not sentences that they are writing… they are writing a paragraph or two paragraphs… and then if I have a longer question then I’m writing a paragraph or something like that… and this takes time. It feels like a waste of time. And while I am writing or they are writing… one of us is waiting for the other to finish and so the time gets eaten up very quickly.

As highlighted in Chapter 2, reading lengthy and sophisticated texts could be difficult for d/Deaf persons with low levels of English literacy. Accordingly, some participants pointed out that it could be “overwhelming” to read enormous amount of text, and thus was not a useful method to communicate with the dentists. Sharing his opinion, a 21-year-old college student stated:

> But this [writing] is not always helpful because there are some d/Deaf people who don't know how to read. They would say "Oh my god, it's too much! It's overwhelming!" I can read this [pointing out to the consent form] because it's more like policy writing… I can read this and I can understand it … But for many d/Deaf people they will see this and say "It's very formal… they see words that they don't understand or recognize and that could be a very big challenge for them. I know dentists use very sophisticated English and writing that a d/Deaf person wouldn't understand.

Confirming his views, another 39-year-old woman mentioned:

> I always write short sentences. Dentists typically write really long paragraphs, it's too much… It's overwhelming I can't get through it all. I like just short exchanges. Sometimes they will look at my responses to questions… and don't seem to get it.

In addition to writing, a few participants mentioned that they preferred reading lips and/or speaking to communicate with their dentists; however, some participants pointed out that they faced difficulty when doing so. As described earlier, participants were not able to read lips when the dentists spoke quickly or did not enunciate their words clearly. "He is very nice, very sweet but when he speaks I don't understand a thing so I have to ask him to repeat quite often," stated a 36-year-old man, explaining why he was not able to lip-read his dentist.

The same participant mentioned that he was able to lip-read another dentist who spoke slowly, enunciated clearly, and kept her messages short. He stated: "She is very clear... she just doesn't sort of speak nonstop, she seems to select the main points that needs to get across and focuses on that. She knows that if she runs on, and keeps talking then I will get lost, she keeps things precise and direct and just in summary." He further mentioned that since the dentist herself was able to lip-read they were both able to communicate with each other through a common medium:

> I don't know what it is but the way she enunciates is clear. Like for that instance when I said the filling had to be re-done. She is the one who explained it to me, and it was so clear the way she explained it. And I am so content with our communication. She can lip read me so it feels that we are on the same playing field, we lip read each other so it's a great match. The man is very sweet but it's much harder to communicate with him.

Lastly, some participants pointed out that the use of radiographic images could act as a supplementary tool to help communicate with the dentists. They mentioned that it was helpful when the dentists used radiographs to show the condition of the teeth, specifically pointing out on the disease areas, and where the procedures were going to be performed. “He showed me the X-ray of my tooth and showed me where the gap was and so there seemed to be a gap in the filling. And then he compared with some other fillings that were similar so that was very clear and a great way to communicate his idea,” stated a 36-year-old man. Another 26-year-old university student concurred by saying:

> On the X-ray pictures he had a red marker and he circled where the problem was and what teeth would have to be removed. And it was clear to me that it wasn’t the teeth that were near the front of my mouth… it was near the back of my mouth.

Further, an older woman stated that the radiograph helped her “validate” what the dentists were saying:

> Pictures are very often clear. It will be a good way to start by taking X-rays because they are very clear, they have the correct and true images of my teeth, so you can see the whole tooth and root and everything. If they can explain where they will be cleaning, what they will remove or doing. The pictures help things be really clear. It’s also essentially just validates or proof of what they are talking about or what they will be doing.

4.2.6. Stage 6: Undergoing dental procedures

In comparison to the treatment planning stage, participants felt relatively comfortable communicating with the dentists when undergoing procedures with few challenges. This was because the participants did not perceive the need to communicate extensively during procedures. They mentioned that as the dentists were mostly working in their mouths at this stage, communication was limited to simple cues (e.g., ‘move head to the right’).

Participants mentioned that since their dentists wore masks during procedures, it was difficult for them to lip-read, and observe the facial expressions of the dentists. “I can’t see the dentist because the dentist is wearing a mask so I can’t see his mouth,” stated a 59-year-old man. The majority of participants mentioned that their dentists understood these challenges, and thus removed their masks when speaking with the participants.

The story of one participant was different, however. This 40-year-old man pointed out that even though he had requested his dentist, multiple times, to remove his mask while speaking to him, the dentist did not accommodate his request. Expressing his frustrations, this participant said: "They were talking with their masks on so I couldn't lip read them. And really the dentist is the worst… he was talking with the mask on and I'm like "Dude why aren't you getting this?" Elaborating, he said:

> I just presumed that he would know better, but whatever, he still does it. He insisted on talking and didn't seem to use any other means of communication, so that was tough. I guess he has never met a deaf person before. If he is working and conducting surgery… sure keep the mask on… but when you have stopped, take the mask off. He keeps it on almost all the time and I don't understand why.

Many participants mentioned that during the procedures, the best way to communicate with the dentists was through simple gestures, and by maintaining eye-contact. "Sometimes the dentist will use his hand shape to gesture 'open mouth' 'close mouth' which is clear for me and I can communicate with the dentist," stated a 59-year-old participant. Emphasizing the effectiveness of gestures during procedures, another participant stated: "We communicated through gestures. When you are in the chair, the gestures are really quite simple." Two other participants stated:

> We sort of gesture and they point at pictures and use "thumbs up" or "thumbs down" [gesturing]… and if everything is okay [gesturing]? (40-year-old man)
>
> I also think it's really important to maintain eye contact and get by a little bit on some basic gestures to communicate. I don't want to be looking all over the place when I'm in the chair… it's not comfortable. I want to be able to kind of have a silent rapport with my dentist when I'm in the chair. (26-year-old woman)

According to the participants, since communication during the procedures was usually basic, they did not feel the need to have an interpreter and/or family member at this stage. Most participants pointed out that during procedures, their family members waited outside the operatory room. "Usually my family is not always in there with me because dentist tells when it's time to start and when it's finished. But usually it is fine because you don't need the interpreter to stay there… but you he can come back when it's done," stated a young college student. Although the majority of participants felt that they did not need an interpreter during procedures, one participant presented a different opinion. Sharing his experiences, a 33-year-old man who did not have an interpreter during the procedure mentioned that his dentist had to stop repeatedly to gesture, which was both time-consuming and frustrating; thus, he preferred to have an interpreter during procedures. He stated:

> It will be best to have the interpreter while the dentist is working in my mouth, the interpreter can sign to me. The one time I went to the dentist, they would be working in my mouth and they would have to pull away and sort of gesture to clearly say open your mouth or close your mouth. So they had to pull away and sort of start and stop and start and stop, and I could tell they were kind of trying, to get frustrated of that. I felt it was a waste of time, moving away to suction, moving away to tell me what to do. I could tell it was a struggle.

In addition to the limited need of interpreters during procedures, most participants stated that, given the restricted space in the operatory room, it might not be suitable to have an interpreter (an additional person) in the room since it could hinder the movements of the dentists. Recalling her experiences regarding these issues, a university student stated:

> There were a lot of people… like five people in one room including myself. I wonder if the dentist had a lot of space... felt free to move as he would normally do. I wonder if the assistant felt they could move as easily as they normally can. So I don't know how comfortable everyone was.

In addition to the issues of space, participants presented competing views on whether or not they would feel comfortable signing during procedures. For example, one man stated that he would prefer having an interpreter since he felt that he would be able to sign freely (move his hands) when sitting on the dental chair during procedures. He said:

> If I am in the chair no one is going to tie down my hands… I will be able to communicate anyway… I can still move my hands… I can still sign a time out and then that would be the signal for everyone to pay attention… so it's not difficult… it's not like I'm in a stray jacket… I can communicate easily.

Another participant who opposed the idea of having an interpreter during procedures, stated:

> I guess sometimes there is a table or tray over me and then they have the bright light on the face as well. So if something is on top of me I would feel I can't really sign. I don't know if it will be easy for me to sign… that's something I'm not sure would look like.

4.3. Summary of the results

The findings of this study reveal a gap between the oral health care system and the needs of persons who are d/Deaf. As a result, the Anglophone d/Deaf population face several challenges on their pathways to oral health care, from the beginning to the end. Broadly speaking, the main barriers identified in this study associate with the following factors: 1) communication challenges; 2) financial limitations; and 3) lack of awareness by dental professionals. It is worthy to note that nuances of these factors were variably present across all the barriers identified in this study. I have summarized the findings according to the five main barriers that the participants faced on their pathway to oral health care. Additionally, I have also classified the findings according to the five dimensions of access as defined by Penchansky and colleagues (1981). Accordingly, the summary of results is as follows:

Choosing a dentist

At the beginning of their oral health care pathway, participants considered two main factors when choosing an accessible dentist: first, a good quality of communication with dentists, and second, the affordability of dental services. Apprehensive about poor communication with hearing dentists, participants preferred to choose a dentist who was either a d/Deaf or proficient in ASL. However, participants were not able to find dentists in Montreal who fit their accessibility requirements.

Making appointments

The next important event in the oral health care pathways of participants was to schedule appointments. However, they faced difficulties in making appointments since the dental staff only contacted them via regular telephones. According to the participants, the use of an inappropriate method of remote communication by the staff reflected their lack of awareness regarding the needs of d/Deaf persons. In order of preference, participants preferred to make appointments through VRS, followed by texting and emailing.

Hiring interpreters

After participants obtained their dental appointment, the next ‘ideal’ step on their oral health care pathway was to hire an interpreter. However, the process of hiring an interpreter was interrupted for the participants for three reasons. First of all, the majority of participants were not able afford the cost of interpretation services. Secondly, given the scarcity of ASL interpreters in Montreal, participants faced an additional challenge of finding an interpreter who was available at the time of their dental appointment. Lastly, many participants did not know that they were not entitled for free interpretation services for dental appointments. Consequently, participants either visited their dentist alone or with a family member, who acted as an interpreter.

Interacting at the reception and the waiting areas

According to the participants, the first time they met the office receptionist, the receptionist started speaking to them. Thus, participants felt that receptionists had little awareness about communication with d/Deaf persons. Additionally, participants experienced similar difficulties in the waiting areas. The most common way dental assistants notified participants of their turns was by calling their names out loud. To counter this challenge, participants recommended that the staff should stand in front of them, or tap on their shoulders, and point towards the operatory.

Communicating with the dentists

Family members as interpreters

Except one person who hired a professional interpreter, most participants communicated with the dentists through the support of family members. However, according to the participants, family members were not effective interpreters because they were neither trained interpreters, nor were fluent in ASL. Consequently, the participants did not completely understand their treatment plans. Therefore, the participants preferred to have a professional interpreter when discussing treatment plans with the dentists.

Direction communication with the dentists

When the participants visited dentists alone, they communicated in various ways, including writing, lip-reading, and through gesturing. According to the participants, writing was not a suitable method to communicate with the dentists. They felt that since writing was a slow process, dentists preferred writing short messages which lacked several details about the treatment process. Also, some participants communicated with the dentists via lip-reading and speaking to the dentists. However, these methods were not suitable for a detailed discussion on treatment planning. Many participants felt that it was visually straining for them to observe the lips and facial expressions of the dentists for a long period of time. These difficulties were also compounded when the dentists spoke at a quick pace, and did not enunciate their words clearly. Moreover, because the dentists wore masks during procedures, it was difficult for the participants to lip-read, and observe the facial expressions of the dentists. Accordingly, many participants mentioned that during procedures, the ideal method to communicate with a dentist was through gesturing, and maintaining eye-contact.

As mentioned earlier, I have also classified the study findings according to the five dimensions of 'access,' as defined by Penchansky and Thomas (1981). Access, which is defined as the degree of 'fit' between the patient and the health care system, includes the following five dimensions: availability, acceptability, accessibility, affordability, and accommodation (Penchansky & Thomas, 1981). Mostly, all the challenges described by the participants fall under the dimension of 'accommodation,' reflecting structural deficiencies in the oral health care system to provide care to persons who are d/Deaf. Below, I have grouped and summarized the findings according to each dimension of access:

Availability

Participants faced challenges in finding 'accessible' dentists, which indicates a possible shortage of dentists trained to provide care to d/Deaf persons. According to the participants, an accessible dentist is the one who is either proficient in ASL, or covers the cost of interpretation services for their dental appointments. Moreover, participants mentioned that access to oral health care for d/Deaf persons highly depends on the availability of ASL interpreters. However, because of the scarcity of ASL interpreters in Montreal, access to oral health care was further compromised for the participants.

Acceptability

Participants expressed hesitation with using family members as interpreters as it often resulted in inadequate communication, as well as raised both confidentiality issues and dependence on family members. Further, the participants did not accept the use of regular telephones and TDD by dental staff as appropriate means of remote communication.

Accessibility

According to Penchansky and Thomas (1981), 'accessibility' implicates the "relationship between the location of health care providers and the location of patients, taking account of patients' transportation resources, and travel time, distance and cost" (p. 128). In this study, there were no issues raised by participants regarding accessibility of oral health care services. Nevertheless, a few participants preferred to visit dental offices near their homes for convenience.

Affordability

A few participants faced difficulties in affording oral health care services due to inadequate dental insurance plans vis-à-vis the high costs of dental services. Moreover, paying for interpretation services ‘out-of-pocket’ for dental appointments presented additional financial challenges for the participants.

Accommodation

The majority of the challenges that I identified in this study fall under the category of accommodation. According to the participants, dental professionals failed to accommodate the needs of d/Deaf persons since they lacked awareness regarding the realities of d/Deafness. Lastly, participants mentioned that the dentists did not take concrete actions to meet basic communication needs of d/Deaf persons.

Chapter 5: Discussion

In this study, I aimed to explore experiences of the Anglophone d/Deaf population regarding access to oral health care services in Montreal. In particular, I focused on the barriers and facilitators of access to oral health care services for this population. Findings of this study revealed that the Anglophone d/Deaf population faces several barriers on their pathways to oral health care. Importantly, these results direct us to solutions that, with the collaboration of the Anglophone d/Deaf community, dental professionals, dental educators, and the government, could improve access to oral health care services for the Anglophone d/Deaf population.

5.1. Study contributions

This research contributes in several ways to both theory and practice regarding access to oral health care for persons with disabilities. To my knowledge, it is the first empirical study aimed at exploring the barriers which an adult d/Deaf population face when accessing oral health care services. The current evidence on both oral health and oral health care of d/Deaf persons is largely focused on the pediatric population. Therefore, by researching the problems of the adult d/Deaf population, this study presents an additional perspective on the topic of oral health care for d/Deaf persons.

Overall, there is little knowledge on the challenges that d/Deaf persons experience on their pathways to oral health care. Only one previous quantitative study, conducted with the parents of d/Deaf children in the UK, provided some evidence on this subject. This study employed a questionnaire as a data collection tool with predetermined categories that was completed by parent(s) of the children under study. Consequently, it is limited in scope, because it does not directly include the perspective of d/Deaf persons.

Previous oral health studies have mainly emphasized the physical condition of hearing loss. As a consequence, they have ignored the interplay of cultural and linguistic factors that shapes the perception of d/Deaf persons related to social issues, including access to oral health care. As Young and Hunt (2011) explained, considering the unique cultural and linguistic aspects of d/Deaf persons in health care systems research is essential to increasing the relevance and implications of studies involving the d/Deaf population. Therefore, by employing a participatory research approach, with a focused ethnographic design, the present study includes both the voices of persons affected by these issues, and explains the context in which these barriers are created, and how can they be improved upon.

5.2. Oral health care pathways of d/Deaf persons in Montreal

The present research is important as it reveals the difficulties the Anglophone d/Deaf population encounter in access to oral health care, as well as helps in understanding realities of d/Deaf persons' lives (e.g., Deaf culture). Further, the participatory research approach has enabled the creation of knowledge that is highly relevant for overcoming the obstacles faced by the Anglophone d/Deaf population. Based on the findings of this study, barriers that the Anglophone d/Deaf population meet are associated with main three factors: communication difficulties, financial constraints, and the lack of awareness by dental professionals. However, as noted earlier, nuances of all three factors are variably present across all the barriers identified in this study.

Choosing a dentist

When choosing a dentist, or deciding to stay with one, the participants considered two main factors: the quality of communication with dentists, and; the costs dentists charged for services. Quality of 'dentist-patient' communication was the primary factor which all participants considered in whether choosing, or staying with, a dentist. Already apprehensive about poor communication with a hearing dentist, participants preferred dentists who were either d/Deaf themselves or fluent in ASL. This situation is comparable to other linguistic minorities (e.g., immigrants), who tend to prefer dentists of ethnic backgrounds same as themselves (Dong, Levine, Loignon, & Bedos, 2011; Mullen, Chauhan, Gardee, & Macpherson, 2007; Zhang, 2008). For example, a study conducted by Dong and colleagues (2011) with Chinese immigrants in Montreal revealed that the latter preferred consulting Chinese dentists to avoid any possible linguistic and cultural barriers associated with dentists of other ethnicities (Dong et al., 2011).

Another factor was the costs at which dentists offered services. However, this finding is possibly not specific to the d/Deaf population, given that many dental patients consider the costs of dental care when choosing a dentists. For instance, Macdonald and colleagues (2015) conducted a study to determine how public views dental care in Quebec. They reported that dental patients tended to compare the prices among dentists when rating the quality of services provided by the dentists (Macdonald et al., 2015). Further, Moshkelgosha and colleagues (2014) who conducted a study with the residents of Shiraz city in Iran revealed that more than 50% of their participants considered ‘cost of dental care’ as the main factor in choosing a dental clinic. In the present study however, the cost of dental care was a secondary factor for most participants, given that the majority had both dental insurance plans as well as good family incomes. However, this finding is probably not representative of d/Deaf persons in Canada given that they generally have a low income (Statistics Canada, 2006a).

Making appointments

Making appointments by telephone was problematic for the participants; yet, staff did not use texting (SMS) or emailing for booking appointments, nor did they have TDDs in their offices. Because the participants were not able to communicate with the dental staff directly, a family member spoke on their behalf. The majority of the participants preferred making appointments via texting (SMS) or emailing, while some of the older participants were also comfortable with using TDDs. My findings regarding the use of TDDs are supported by Iezzoni and colleagues (2004), who conducted a qualitative study to explore health care experiences of d/Deaf persons in the US. They found that although d/Deaf persons preferred making appointments via TDD, the health care professionals did not have TDDs as they did not want to learn how to use it (Iezzoni, 2004). The recommendation to use TDD as an alternative to telephone was also proposed in a British study conducted by Champion & Holt (2000), who explored the perceptions of parents of d/Deaf children regarding access to oral health care. These findings differ from my study as majority of the participants did not perceive TDD to be the ideal method for booking appointments, with many calling it “outdated” and “tedious.” A possible reason for these differences could be because the other cited studies were conducted at a time when texting was not as popular as it is in the present-day.

Amongst the currently available remote communication options for d/Deaf persons, participants in my study preferred booking appointments via texting (SMS) and/or emailing. Perhaps, this finding is not generalizable to all d/Deaf persons given that my sample mostly constituted of young d/Deaf adults (mean sample age: 37.6 years). Previous studies have shown that the preference of a d/Deaf person towards a particular technology for remote communication is associated with their age. For example, Pilling & Barrett (2008) who conducted a survey in the UK found that d/Deaf persons under the age of 30 preferred using SMS, whereas TDD was favored by the middle aged d/Deaf persons (age 30-49) (Pilling & Barrett, 2008).

Video Relay Services (VRS), which is not yet available in Canada, was another remote communication method that participants discussed. VRS allows a d/Deaf person to communicate with a hearing person in sign language via a relay operator (CRTC, 2015). According to the participants, VRS would be the ideal method of booking appointments once it becomes available in the fall of 2016. This finding is supported by the recommendations made by Steinberg and colleagues (2006), who also proposed that VRS is the best solution to overcome the present challenges related to telephone communication of d/Deaf persons with dental staff. I however did not find any other studies confirming the merits of VRS in dentistry or health care settings.

Hiring ASL interpreters

As illustrated in my findings, the majority of the participants could not hire interpreters for their dental appointments for two main reasons: 1) financial limitations and 2) limited availability of ASL interpreters. d/Deaf persons have access to free interpretation services for health care appointments in Canada. However, because the Canada Health Act does not include oral health care services, they have to pay out-of-pocket to cover the cost of interpretation services for dental appointments. Even though the majority of participants had good family incomes, they were not able to afford the additional expenses of interpretation for their dental appointments. The local ASL interpretation agency in Montreal charges 55 dollars per hour with a 2-hour minimum (CCSMM, 2014). Therefore, it could be difficult for the majority of d/Deaf persons in Canada, who belong to a low socio-economic group, to afford interpretation services for dental appointments.

In addition to the challenge of the cost of interpreters, participants pointed out that there was a lack of ASL interpreters working in Montreal. Therefore, even if d/Deaf persons had access to free interpretation services, particularly the Anglophone d/Deaf community would have still faced challenges in finding an interpreter for their dental appointments. As the participants described, because Montreal is a majority French-speaking city, ASL interpreters may not prefer to work here. These findings are similar to those of Parise (1999), who conducted a study about access to health care services for the Anglophone d/Deaf population in Montreal. She reported that even though the Anglophone d/Deaf persons had access to interpretation services for free, they were not able to find an available interpreter at the time of their health care appointment.

Interacting at the reception and the waiting areas

For a typical patient, a dental appointment begins with meeting a receptionist at the front desk, followed by a wait in the waiting areas, prior to being seen by a dentist. For d/Deaf persons, as the participants explained, both interacting with the receptionists and being aware of their turns could be problematic. In this study, many participants mentioned that the first time they met the receptionist, the latter started speaking instantly as they would do with a hearing person. Indeed, it is difficult to tell if a person is d/Deaf by simply looking at him or her (Shohet & Bent, 1998), which could have been the possible reason for the staff to react in this way. However, as the participants mentioned, even after realizing that they were d/Deaf, the staff was not able to communicate appropriately with them. Possibly, the staff lacked awareness about the lives of d/Deaf persons, especially the way they communicate. Previous studies have also revealed similar findings confirming that the health care office staff tend to lack such awareness (Emond et al., 2015; Iezzoni, 2004; Kuenburg et al., 2016; Ubido et al., 2002).

Another concern that the participants raised was about not being aware of their turn when their names were called in the waiting areas. Consequently, they had to continuously focus on watching the staff to ensure they did not miss their turn. In waiting areas of clinics, hearing people normally relax, read magazines and so forth; d/Deaf persons have an added burden of being vigilant so that they do not miss their turn (Thew, Smith, Chang, & Starr, 2012). Other studies support the finding that the staff in health care settings call out names of d/Deaf persons (Iezzoni, 2004; Ubido et al., 2002), which the latter are not able to hear. For instance, an American study conducted by Iezzoni and colleagues (2004) reported that many d/Deaf persons miss their appointments, and have to continuously focus on watching the staff to ensure they do not miss their turn to meet the doctor (Iezzoni, 2004).

In my study, the participants suggested that the best approach to gain attention of d/Deaf patients in waiting areas is to stand in front of them and point towards (gesture) the operatory room. Similar suggestions were made by Emond and colleagues (2015), who recently conducted a study with d British Sign Language (BSL) users. They also proposed the idea of placing visual alerts (e.g., flashing lights) in the waiting area so that d/Deaf persons can see when it is their turn. Moreover, other authors have also recommended to give vibrating pagers to inform d/Deaf patients when clinician is ready to attend to them (Iezzoni, 2004; Scheier, 2009).

Communicating with the dentists

Participants found it difficult to communicate with their dentists. The nature of these difficulties differed based on whether they communicated with the dentists through the help of a family member, or directly.

Family members as interpreters

Given their poor access to professional interpreters, most participants communicated with the dentists through a family member who acted as an interpreter. Using family members as interpreters was however not a very useful approach as the family members were neither fluent in ASL, nor trained as an interpreter. As a result, the family members were not able to effectively convey the messages of the dentists to the participants and vice versa. Citing similar reasons for why family members are not as effective as professional interpreters, previous studies have also shown that d/Deaf persons face challenges with communicating with health professionals when family members act as interpreters (Lieu et al., 2007; Scheier, 2009; Wood, 2002). For example, Steinberg and colleagues (2006) found that when family members act as interpreters, d/Deaf persons often feel excluded from the conversation and do not completely understand doctors' messages.

Other studies have also found that working with family members in health care settings could raise privacy concerns for d/Deaf persons (Scheier, 2009; Steinberg et al., 2006). For example, a patient might hesitate to request an HIV test if their mother is interpreting (Scheier, 2009). In this study participants did not have similar concerns, perhaps because the dental treatment they received was mostly limited to cleaning, extractions or fillings. Nevertheless, because many sexually transmitted diseases (e.g., Herpes simplex virus) have oral manifestations (e.g., Herpetic gingivostomatitis, Herpes labialis) (Bruce & Rogers, 2004), privacy concerns with family members acting as interpreters may arise in dental settings as well. Therefore, it is in the best interest of both the dentists and the d/Deaf patients to communicate through a professional interpreter instead of a family member.

Direct communication with the dentists

Congruent with the findings of several studies (Iezzoni, 2004; Meador & Zazove, 2005; Steinberg et al., 2006; A. Steinberg et al., 2002), participants also faced challenges in communicating directly with the practitioners. In the absence of interpreters, d/Deaf persons usually communicate with health care professionals by writing and/or lip-reading-and-speaking and/or gesturing (Emond et al., 2015; Harmer, 1999; Kuenburg et al., 2016). In this study, the participants mentioned that the dentists did not realize the consequences of communication barriers with d/Deaf patients, as well as held misconceptions regarding the appropriate methods of communication. These findings are similar to what was cited in numerous other health care studies (Ebert & Heckerling, 1995; Iezzoni, 2004; Ubido et al., 2002; Zazove et al., 1993).

Writing

Participants mentioned that, in the absence of interpreters, the dentists resorted to writing to communicate. However, as shown in these findings, writing was not an effective method for communication. Indeed, because the majority of d/Deaf persons have low literacy, they can find it difficult to communicate through writing and reading (MacKinney, Walters, Bird, & Nattinger, 1995). In my study, participants faced difficulties in communicating in writing because they were not able to understand the vocabulary, with many complaining that the dentists used ‘sophisticated’ language. Another reason was that the dentists tended to write short messages to save time, which was difficult to decipher. As a consequence, they often did not receive complete information, which lead to confusion. These findings are similar to those of Iezzoni and colleagues (2004), who found that d/Deaf patients often receive incomplete information by health care providers when communicating through writing.

As noted earlier, the participants in my study mentioned that dentists tended to choose inappropriate methods to communicate with d/Deaf persons, when an interpreter was not around. A possible explanation for this situation is that the dentists lacked awareness about appropriate modalities of communication with d/Deaf person. The results of Ebert and Heckerling (1995), who conducted a survey with a group of physicians to explore their perceptions regarding the most effective methods to communicate with d/Deaf persons, confirm this finding. They found that 37% of physicians felt that writing and lip-reading were the best ways to communicate with d/Deaf persons in clinical settings.

Lip-reading

As pointed out earlier, health care professionals tend to believe that lip-reading is an effective way to communicate with d/Deaf persons. However, because only 30-45% of English sounds are visible on the lips, it is difficult for d/Deaf persons to understand the speech of a person by lip-reading alone (Iezzoni, 2004). In addition to the linguistic barriers associated with lip-reading, participants also faced problems in reading lips because the dentists wore masks while speaking to them. While acknowledging that wearing a mask is an important clinical protocol, participants proposed that dentists should try to wear them only when absolutely necessary. This is similar to the findings of Champion and Holt (2000), who reported that almost two-thirds of respondents mentioned that dentists tended to wear masks when speaking.

Further to this point, participants faced an added challenge of lip-reading the dentists who spoke in French accents. d/Deaf persons find it challenging to read the lips of persons with foreign accents, as the latter pronounces vowels and syllables using different mouth shapes than persons with English-speaking origins (Campbell et al., 1997). Therefore, to overcome these challenges, participants suggested that the dentists should use simple gestures instead of speaking, especially during procedures when they cannot remove their masks.

5.3. Limitations of this study

This study was conducted in Montreal, Quebec, Canada, and specifically focused on the d/Deaf Anglophone community. Therefore, my findings may not be completely transferable to other social, political, and cultural contexts. Nonetheless, the barriers that I identified in this study may be relevant to other regions, especially where the oral health care delivery system is similar to Quebec – with the caveat that the linguistic issues may be unique to Quebec. The results of this study may not be applicable to d/Deaf persons who use other regional variations of sign language (e.g., British Sign Language) whether in Montreal or elsewhere because of the linguistic differences. Yet, my findings should be relevant to all d/Deaf ASL users, regardless of their geographical locations. One final limitation of my study is that I did not explore the experiences and perceptions of dental professionals about providing care to d/Deaf persons. Future research should therefore focus on understanding the perspectives of dental professionals on this topic.

5.4. Strengths of this study

I adopted a focused ethnography research design, which is a suitable methodology to explore health care related issues of a discrete community, within a specific context (Roper & Shapira, 2000). Focused ethnography is particularly a useful methodology when studying issues surrounding health care systems as it provides an in-depth, contextual, understanding. Therefore, when exploring the oral health care experiences of the d/Deaf community, which is unique in its own ways, focused ethnography was highly pertinent.

Also, this study is based on the principles of participatory research; therefore I engaged d/Deaf persons in the entire research process. As Cargo and Mercer (2008) explained "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" (p. 327). In this study, I developed research partnerships among health care researchers, d/Deaf advocacy organizations, and local rehabilitation centers for d/Deaf persons. This partnership was important in understanding oral health care issues that were most important to the local d/Deaf community. As a result, I was able to develop my project around key issues of, and as raised by, the d/Deaf population.

Another strength of this project is that I employed a maximum variation sampling technique. This sampling technique enabled me to capture the nuances of both cultural and linguistic diversity within the d/Deaf population. In their article, 'Research with d/Deaf people,' Young and Hunt (2011, p. 5) recommended that "whether carrying out large-scale survey research, or more modestly seeking to record the demographics of a participating sample, there is a requirement to capture the identity/self-definition/personal characteristics of those involved." Therefore, by taking into account the unique characteristics of the d/Deaf community, I was able to provide culturally-sensitive explanations on the oral health care issues of this community. This detailed explanation should be helpful in many ways, especially when developing oral health care interventions for the d/Deaf population.

5.5. Recommendations

As illustrated by my findings, the d/Deaf population faces several barriers on their oral health pathways. According to the participants, these challenges mainly stem from structural deficiencies in the society. The World Health Organization emphasizes that it is the responsibility of the society to eliminate accessibility barriers for persons with disabilities (WHO, 2011). According to my findings, several sectors in society play important roles in influencing the outcome of oral health care for d/Deaf persons. Therefore, I have made a few recommendations to four relevant groups, closely involved in oral health care services, including, the government, dentists and the dental office staff, dental schools, dental educators and researchers, and the Order of Dentists of Quebec. Some of these recommendations draw from those proposed by Rashid-Kandvani (2013) who conducted a similar study on access to oral health care for persons using wheelchairs in Montreal.

Government

The Canadian government is one of the signatories of the UN Convention on Rights of Persons with Disabilities, and is highly committed to eradicate discrimination against persons with disabilities (Rashid-Kandvani, 2013). As highlighted above, both the oral health care system and dental professionals fell short of accommodating the needs of d/Deaf persons. According to Article 2 of the United Nations Convention on the Rights of Persons with Disabilities, denying reasonable accommodation on the basis of disability constitutes a form of discrimination. Therefore, the government should work with relevant sectors in society to remove the barriers in the oral health care pathways of d/Deaf persons. I therefore urge the Quebec government to consider the following recommendations:

- Since the lack of access to interpretation services is a significant barrier for d/Deaf persons during oral health care, the government should allocate adequate funds to cover the costs of sign language interpretation services for every dental appointment.
- The government should encourage the ODQ and dental schools to develop policies and education modules directed to dental professionals for providing care to d/Deaf persons.
- The government should subsidize the costs of oral health care services as well as provide special insurance plans to address the financial barriers for d/Deaf persons.

Dentists and the dental office staff

As dentists and the dental office staff works closely with d/Deaf persons when providing oral health care, they have an important responsibility to help facilitate accessible services to their d/Deaf patients. Therefore, I have the following recommendations for dentists and their staff:

- The dental office staff should schedule appointments with d/Deaf persons either via VRS, texting (SMS), or emailing.
- In the waiting areas, the staff should either stand in front of d/Deaf persons and gesture towards the operatory room, and/or tap on the shoulders of d/Deaf person to notify them of their turns.
- During consultations, the dentists should remove their masks, speak slowly, and maintain constant eye-contact when speaking with a d/Deaf person. Further, when communicating via writing, the dentists should write short messages using simple language.
- When performing a dental procedure, the dentists should maintain constant eye-contact with the d/Deaf persons, and use simple gestures to communicate simple instructions (e.g. ‘open mouth’ ‘close mouth’).

Dental schools, dental educators, and researchers

As Kandvani pointed out (2013), dental school is the first place where future dental professionals learn about their social responsibilities. Therefore, dental students should receive adequate clinical training to provide care to d/Deaf persons. Further, dental schools should provide sufficient opportunities to dental students for meeting d/Deaf persons regularly, whether in clinics, or through outreach activities. These regular meetings with d/Deaf persons could help in sensitizing dental students regarding the realities of d/Deaf persons. My recommendations to the dental schools and dental educators are as follows:

- Dental educators should encourage dental students to learn sign language, at least at the basic level to be able to greet and have simple conversations with d/Deaf persons.
- The dental educators should provide didactic and clinical training to explain the needs of d/Deaf patients (e.g., communication techniques) as well as the ways in which dentists could successfully accommodate these needs.

- The dental schools in Quebec should develop residency programs to provide specialty training to dental residents to care for persons with disabilities.
- When designing research studies, instead of focusing solely on the physical condition of hearing loss, oral health researchers should also consider the cultural and linguistic aspects of d/Deafness. Future research should also be directed towards understanding the experiences and perceptions of dentists with regards to providing care d/Deaf persons.

Order of Dentists of Quebec (ODQ)

The ODQ has the mission to maintain quality oral health care services by ensuring that dental professionals adhere to high standards of practice and ethical conduct, and to promote oral health amongst the residents of Quebec (ODQ, 2015). Accordingly, the ODQ is responsible for assessing the quality standards of dental clinics, and providing continuing dental education (CDE) for dental professionals (Rashid-Kandvani, 2013). Therefore, the ODQ has the potential of significantly improving access to oral health care services for d/Deaf persons. Thus, I recommend the following to the ODQ:

- The ODQ should develop evidence-based guidelines constituting a checklist of factors that ensures complete accessibility of oral health care services for d/Deaf persons.
- The ODQ should develop continuing dental education courses to train dentists to communicate with d/Deaf persons, including working with a sign language interpreter.
- The ODQ should take collaborative actions with the Quebec government to ensure that d/Deaf persons have access to free interpretation services for their dental appointments.

Chapter 6. Conclusion

This study was designed to understand the barriers that the Anglophone d/Deaf population face when accessing oral health care services. Although several studies have confirmed that d/Deaf persons encounter numerous difficulties in access to health care, there is a dearth of research about their access to oral health care services. Therefore, I addressed this crucial gap in the literature by conducting a detailed investigation of the barriers and facilitators of access to oral health care for d/Deaf persons. The three main questions which drove this study were: How do d/Deaf persons experience access to oral health care services? What are the barriers they face when doing so? And what are the potential solutions to overcome these challenges?

Overall, the findings of this study revealed that the Anglophone d/Deaf population face several barriers on their oral health care pathways. In broad terms, these barriers include: poor access to ASL interpreters, difficulties interacting with the office staff (both on telephone and waiting areas), and communication barriers with the dentists, during both consultation and procedures. Participants offered a variety of suggestions to overcome these barriers, including: 1) the Quebec government should cover the cost of interpreters for dental appointments; 2) the office staff should use VRS, text (SMS) or e-mail for booking appointments; and 3) the dentists should inquire the patients for their preferred mode of communication, remove masks when speaking, and use gestures when performing dental procedures.

In the end, this study confirms that the Anglophone d/Deaf population in Montreal experiences inequalities in access to oral health care. Therefore, there is a need for concrete actions from a wide range of groups, including the Quebec government, ODQ, dental educators, and the dentists themselves. I urge the Quebec government, the dental profession, dental schools and organizations representing d/Deaf persons to work in collaboration in order to improve access to oral health care services for d/Deaf persons. I hope that the recommendations made in this study will lead to concrete actions to effect positive change in the near future.

7. References

Aday, L., & Andersen, R. (1974). A framework for the study of access to medical care. *Health Services Research, 9*(3), 208-220.

Ajami, B. A., Shabzendedar, M., Rezay, Y. A., & Asgary, M. (2007). Dental treatment needs of children with disabilities. *J Dent Res Dent Clin Dent Prospects, 1*(2), 93-98.

Ajayi, D. M., & Arigbede, A. O. (2012). Barriers to oral health care utilization in Ibadan, South West Nigeria. *Afr Health Sci, 12*(4), 507-513.

Al-Qahtani, Z., & Wyne, A. H. (2004). Caries experience and oral hygiene status of blind, deaf and mentally retarded female children in Riyadh, Saudi Arabia. *Odonto-Stomatologie Tropicale, 27*(105), 37-40.

Al Sarheed, M., Bedi, R., Al Khatib, M., & Hunt, N. (2006). Dentists' attitudes and practices toward provision of orthodontic treatment for children with visual and hearing impairments. *Special Care in Dentistry, 26*(1), 30-36.

Al Sarheed, M., Bedi, R., & Hunt, N. P. (2001). Attitudes of dentists, working in Riyadh, toward people with a sensory impairment. *Special Care in Dentistry, 21*(3), 113-116.

Al Sarheed, M., Bedi, R., & Hunt, N. P. (2003). Traumatised permanent teeth in 11-16-year-old Saudi Arabian children with a sensory impairment attending special schools. *Dental Traumatology, 19*(3), 123-125.

Amarasena, N., Ekanayaka, A. N. I., Herath, L., & Miyazaki, H. (2002). Tobacco use and oral hygiene as risk indicators for periodontitis. *Community Dentistry and Oral Epidemiology, 30*(2), 115-123.

Andrews, Leigh, & Weiner. (2004). *Deaf people: evolving perspectives from pyschology education and sociology*. Boston, MA.

Andrews, J., Leigh, I., & Weiner, M. (2004). *Deaf people: evolving perspectives from pyschology education and sociology*. Boston, MA.

Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qual Health Res, 13*(6), 871-883.

Badger, T., &, & Jones, E. (1990). Deaf and hearing children's conception of the body interior. *Pediatric Nursing, 16*(2), 201-205.

Barnett, S. (2002). Communication with deaf and hard-of-hearing people: a guide for medical education. *Academic Medicine, 77*(7), 694-700.

Barnett, S., & Franks, P. (2002). Health care utilization and adults who are deaf: Relationship with age at onset of deafness. *Health Services Research, 37*(1), 105-120.

Barnett, S., Klein, J. D., Pollard, R. Q., Jr., Samar, V., Schlehofer, D., Starr, M., . . . Pearson, T. A. (2011). Community participatory research with deaf sign language users to identify health inequities. *Am J Public Health, 101*(12), 2235-2238.

Benner, P. (1994). *Interpretive phenomenology: embodiment, caring, ethics in health and illness*. London, New Dehli: SAGE Publications, International Educational and Professional Publisher.

Boyle, J. (1994). *Styles of ethnography*. CA: Thousand Oaks

Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Services Research, 42*(4), 1758-1772.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Brown, K., & Balkany, T. (2007). Benefits of bilateral cochlear implantation: a review. *Current Opinion in Otolaryngology & Head and Neck Surgery, 15*(5).

Bruce, A., & Rogers, R., 3rd. (2004). Oral manifestations of sexually transmitted diseases. *Clin Dermatol, 22*(6), 520-527.

Burch, S. (2000). In a Different Voice: Sign Language Preservation and America's Deaf Community. *Bilingual Research Journal, 24*(4), 443-464.

CAD. (2012a). Deaf Culture vs. Medicalization. Retrieved from http://www.cad.ca/deaf_culture_vs._medicalization.php

CAD. (2012b). Employment and Employability. Retrieved from http://www.cad.ca/employment_and_employability.php

CAD. (2012c). Health Care. Retrieved from http://www.cad.ca/health_care.php

CAD. (2012d). Literacy. Retrieved from http://www.cad.ca/literacy.php

CAD. (2012e). Statistics on Deaf Canadians. Retrieved from http://www.cad.ca/statistics_on_deaf_canadians.php

CAHS. (2014). *Improving access to oral Health care for vulnerable people living In Canada*. Retrieved from

Campbell, R., Zihl, J., Massaro, D., Munhall, K., & Cohen, M. M. (1997). Speechreading in the akinetopsic patient, L.M. (0006-8950 (Print)).

Canadian Institute of Health Research, N. S. a. E. R. C. o. C., & Social Sciences and Humanities Research Council of Canada. (2010). Tri-Council Policy Statement: Ethical conduct for research involving humans.

Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: strengthening its practice. *Annual Review of Public Health, 29*, 325-350.

CCSMM. (2014). ASL Interpreting Service Retrieved from http://www.ccsmm.net/asl2014/grille.php

CDA. (2010). Position Paper on Access to Oral Health Care for Canadians. Retrieved from http://www.cda-adc.ca/_files/position_statements/accessToCarePaper.pdf

CDC. (2015). Early Intervention: Communication and Language Services for Deaf and Hard-of-Hearing Children: Centers for Disease Control and Prevention

Champion, J., & Holt, R. (2000). Dental care for children and young people who have a hearing impairment. *British Dental Journal, 189*(3), 155-159.

Chan, L. (2014). *"Dying People Don't Belong Here": How cultural aspects of the acute medical ward shape care of the dying* (Doctor of philosophy), McGill University, Montreal, QC, Canada.

Corradetti, C. (2015). The Frankfurt School and Critical Theory. *Internet Encyclopedia of philosophy*.

CRTC. (2015). Video Relay Service (VRS). Retrieved from http://www.crtc.gc.ca/eng/phone/acces/rela.htm

DiPietro, L., Knight, C., & Sams, J. (1981). Health Care Delivery for Deaf Patients: The Provider's Role. *American Annals of the Deaf, 126*(2), 106-112.

Dong, M., Levine, A., Loignon, C., & Bedos, C. (2011). Chinese immigrants' dental care pathways in Montreal, Canada. *Journal (Canadian Dental Association), 77*(b131).

Dougall, A., & Fiske, J. (2008). Access to special care dentistry, part 2. Communication. *British Dental Journal, 205*(1), 11-21.

Ebert, D., & Heckerling, P. (1995). Communication with deaf patients. Knowledge, beliefs, and practices of physicians. *Jama, 273*(3), 227-229.

Emerson, R. (1976). Social-Exchange Theory. *Annual Review of Sociology, 2*, 335-362.

Emond, A., Ridd, M., Sutherland, H., Allsop, L., Alexander, A., & Kyle, J. (2015). Access to primary care affects the health of Deaf people. *Br J Gen Pract, 65*(631), 95-96.

Gibbons, C. (1985). Deaf children's perception of internal body parts. *Maternal-Child Nursing Journal, 14*(1), 37-46.

Green, & Mercer. (2001). Can Public Health Researchers and Agencies Reconcile the Push From Funding Bodies and the Pull From Communities? *American Journal of Public Health, 91*(12), 1926-1929.

Grembowski, D., Andersen, R., & Chen, M. (1989). A public health model of the dental care process. *Med Care Res Rev, 46*(4), 439-496.

Grenfell, M. (2010). Being critical: the practical logic of Bourdieu's metanoia *Critical Studies in Education, 51*(1), 85-99.

Guay, A. (2004). Access to dental care: solving the problem for underserved populations. *J Am Dent Assoc., 135*(11), 1599-1605.

Harmer, L. (1999). Health care delivery and deaf people: practice, problems, and recommendations for change. *Journal of Deaf Studies & Deaf Education, 4*(2), 73-110.

Harris, J., & Bamford, C. (2001). The uphill struggle: services for Deaf and hard of hearing people - issues of equality, participation and access. *Disability & Society, 16*(7), 969-979.

Higginbottom, G., Pillay, J., & Boadu, N. (2013). Guidance on Performing Focused Ethnographies with an emphasis on healthcare research. *The Qualitative Report, 18*, 1-16.

Hiranandani, V. (2005). Towards a Critical Theory of Disability in Social Work. *Critical Social Work, 6*(1).

Holloway, I. (1997). *Basic concepts for Qualitative Research*. London: Blackwell Science.

Horkheimer, M. (1982). *Critical Theory*. New York: Seabury Press.

Iezzoni, L. I. (2004). Communicating about Health Care: Observations from Persons Who Are Deaf or Hard of Hearing. *Annals of Internal Medicine, 140*(5), 356.

Jain, M., Bharadwaj, S. P., Kaira, L. S., Bharadwaj, S. P., Chopra, D., Prabu, D., & Kulkarni, S. (2013). Oral health status and treatment need among institutionalised hearing-impaired and blind children and young adults in Udaipur, India. A comparative study. *Oral Helath & Dental Management, 12*(1), 41-49.

Jain, M., Mathur, A., Kumar, S., Dagli, R. J., Duraiswamy, P., & Kulkarni, S. (2008). Dentition status and treatment needs among children with impaired hearing attending a special school for the deaf and mute in Udaipur, India. *Journal of Oral Science, 50*(2), 161-165.

Jones. (2002). Deafness as Culture: A Psychological Perspective. *Disability Studies Quarterly, 22*(2).

Kamatchy, K. R., Joseph, J., & Krishnan, C. G. (2003). Dental caries prevalence and experience among the group of institutionalized hearing impaired individuals in Pondicherry--a descriptive study. *Indian Journal of Dental Research, 14*(1), 29-32.

Kanika, A., Kalpana, B., Meenu, M., & Mohita, M. (2011). Oral health status of sensory impaired children in Delhi and Gurgaon. *International Journal of Dental Clinics, 3*(2), 21-23.

Kaplan, D. M., & Puterman, M. (2010). Pediatric cochlear implants in prelingual deafness: medium and long-term outcomes. *Israel Medical Association Journal: Imaj, 12*(2), 107-109.

Khang, P. (2000). *Health Care Access Behaviors in the Deaf Community of Connecticut.* (Master of Public Health), University of Connecticut.

Kuenburg, A., Fellinger, P., & Fellinger, J. (2016). Health Care Access Among Deaf People. *Journal of Deaf Studies and Deaf Education, 21*(1), 1-10.

Lieu, C., Sadler, G., Futterton, J., & Stohlman, P. (2007). Communication strategies for nurses interacting with deaf patients. *MedSurg Nursing, 16*(4), 239-244.

Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Literacy Ontario. (1998). Literacy Profile of Ontario's Deaf and Hard of Hearing Adults.

Loesche, W. (1996). Microbiology of Dental Decay and Periodontal Disease. In S. Baron (Ed.), *Medical Microbiology*. Galveston (TX): Univeristy of Texas Medical Branch

Macdonald, M., Beaudin, A., & Pineda, C. (2015). What do patients think about dental services in Quebec? Analysis of a dentist rating website. *Journal (Canadian Dental Association), 81*(f3).

MacDougall, J. (2012). *Being Deaf in Yucatec Maya Community: Communcation and Identity Negotiation* McGill University

MacKinney, T., Walters, D., Bird, G., & Nattinger, A. (1995). Improvements in preventive care and communication for deaf patients: results of a novel primary health care program. (0884-8734 (Print)).

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *Lancet, 358*.

McIlroy, G., & Storbeck, C. (2011). Development of Deaf Identity: An Ethnographic Study. *Journal of Deaf Studies and Deaf Education, 16*(4), 494-511.

Meador, H. E., & Zazove, P. (2005). Health care interactions with deaf culture. *J Am Board Fam Pract, 18*(3), 218-222.

Montgomery, P., & Bailey, P. H. (2007). Field notes and theoretical memos in grounded theory. *West J Nurs Res, 29*(1), 65-79.

Moshkelgosha, V., Mehrzadi, M., & Golkari, A. (2014). The Public Attitude Towards Selecting Dental Health Centers. *Journal of Dentistry, 15*(3), 129-134.

Mullen, K., Chauhan, R., Gardee, R., & Macpherson, L. (2007). Exploring issues related to attitudes towards dental care among second-generation ethnic groups. *Diversity in Health and Social Care, 4*(2), 91-99.

Niparko, J. K., & Blankenhorn, R. (2003). Cochlear Implants in Young Children. *Mental Retardation and Developmental Disabilities Research Reviews, 9*(4), 267-275.

ODQ. (2015). Mission Statement. Retrieved from http://www.odq.qc.ca/TheOrdre/Missionstatement/tabid/163/language/en-US/Default.aspx

Oliver, M. (1998). Theories of disability in health practice and research *British Medical Journal, 317*, 1446-1449.

Oredugba, F. A. (2004). Oral health care knowledge and practices of a group of deaf adolescents in Lagos, Nigeria. *Journal of Public Health Dentistry, 64*(2), 118-120.

Parise, N. (1999). *Breaking Cultural Barriers to Health Care: The Voice of the Deaf.* McGill University.

Patton. (1990). *Qualitative evaluation and research methods* Beverly Hills, CA: Sage.

Patton. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research, 34*(5 Pt 2), 1189-1208.

Penchansky, R., & Thomas, J. (1981). The concept of access: definition and relationship to consumer satisfaction. *Med Care, 19*(2), 127-140.

Penttinen, J. T. J. (2015). Connectivity and Payment *The Telecommunications Handbook* (pp. 101-133): John Wiley & Sons, Ltd.

Pilling, D., & Barrett, P. (2008). Text communication preferences of deaf people in the United Kingdom. (1081-4159 (Print)).

RAMQ. (2015). Dental Services. Retrieved from http://www.ramq.gouv.qc.ca/en/citizens/health-insurance/healthcare/Pages/dental-services.aspx

Rashid-Kandvani, F. (2013). *Access to dental services for people using a wheelchair.* McGill Univeristy

Reagan, T. (1995). A sociocultural understanding of deafness: American sign language and the culture of deaf people. *International Journal of Intercultural Relations, 19*(2), 239-251.

Reddy, V. K., Chaurasia, K., Bhambal, A., Moon, N., & Reddy, E. K. (2013). A comparison of oral hygiene status and dental caries experience among institutionalized visually impaired and hearing impaired children of age between 7 and 17 years in central India. *Journal of the Indian Society of Pedodontics & Preventive Dentistry, 31*(3), 141-145.

Reddy, V. K., Kshitij, C., Ajay, B., Ninad, M., & Reddy, E. K. (2013). A comparison of oral hygiene status and dental caries experience among institutionalized visually impaired and hearing impaired children of age between 7 and 17 years in central India. *Journal of Indian Society of Pedodontics and Preventive Dentistry, 31*(3), 141-145.

Romer, M., Dougherty, N., & Amores-Lafleur, E. (1999). Predoctoral education in special care dentistry: paving the way to better access? *ASDC J Dent Child, 66*(2), 132-135, 185.

Roper, J., & Shapira, J. (2000). *Ethnography in nursing research*. Thousand Oaks, CA: Sage Publications.

Roper

Shapira. (2000). *Ethnography in nursing research*. Thousand Oaks, CA: Sage Publications.

Russell, C., & Gregory, D. (2003). Evaluation of qualitative research studies. *Evidence Based Nursing, 6*(2), 36-40.

Sandeep, V., Vinay, C., Madhuri, V., Rao, V. V., Uloopi, K. S., & Sekhar, R. C. (2014). Impact of visual instruction on oral hygiene status of children with hearing impairment. *Journal of the Indian Society of Pedodontics & Preventive Dentistry, 32*(1), 39-43.

Sanjay, V., Shetty, S. M., Shetty, R. G., Managoli, N. A., Gugawad, S. C., & Hitesh, D. (2014). Dental health status among sensory impaired and blind institutionalized children aged 6 to 20 years. *Journal of International Oral Health, 6*(1), 55-58.

Scheier, D. B. (2009). Barriers to health care for people with hearing loss: a review of the literature. *J N Y State Nurses Assoc, 40*(1), 4-10.

Schwenk, D. M., Stoeckel, D. C., & Rieken, S. E. (2007). Survey of special patient care programs at U.S. and Canadian dental schools. *Journal of Dental Education, 71*(9), 1153-1159.

Shah, S., & , & Priestley, M. (2001). *Better services 2001, better health, the health care experience of Black and minority ethnic disabled people*. Leeds, UK: Leeds Involvment Project.

Shahrabi, M., Mohandes, F., & Seraj, B. (2007). Assessing DMFT index in 12 years old students attending hearing impaired schools in Tehran. *Journal of Dental Medicine, 19*(4), 102-106.

Shohet, J., & Bent, T. (1998). Hearing loss: the invisible disability. *Postgraduate medicine, 104*(3), 81-81.

Shyama, M., Al-Mutawa, S. A., Morris, R. E., Sugathan, T., & Honkala, E. (2001). Dental caries experience of disabled children and young adults in Kuwait. *Community Dental Health, 18*(3), 181-186.

Simon, E. N., Matee, M. I., & Scheutz, F. (2008). Oral health status of handicapped primary school pupils in Dar es Salaam, Tanzania. *East African Medical Journal, 85*(3), 113-117.

Singh, N., Kaur, G., Gumber, P., & Kaur, N. (2012). Oral Health Status of 6 to 15 year old deaf and blind children of Sriganganagar. *International Journal of Oral Health Research & Review, 1*(1).

Smeijers, A., & Pfau, R. (2009). Towards a treatment for treatment: On communication between general practitioners and their deaf patients. *The Sign Language Translator and Interpreter, 3*, 1-14.

Sparrow, R. (2005). Defending Deaf Culture: The Case of Cochlear Implants*. *Journal of Political Philosophy, 13*(2), 135-152.

Statistics Canada. (2006a). Facts on Hearing Limitations *Participation and Activity Limitation Survey* Statistics Canada.

Statistics Canada. (2006b). Participation and Activity Limitation Survey 2006: A Profile of Assitive Technology for People with Disabilities: Statistics Canada

Statistics Canada. (2006c). Participation and Activity Limitation Survey 2006: Analytical Report

Steinberg, Barnett, S., Meador, H., Wiggins, E., & Zazove, P. (2006). Health care system accessibility. Experiences and perceptions of deaf people. *J Gen Intern Med, 21*(3), 260-266.

Steinberg, A., Wiggins, E., Barmada, C., & Sullivan, V. (2002). Deaf women: experiences and perceptions of healthcare system access. *J Womens Health (Larchmt), 11*(8), 729-741.

Steinberg, A. G., Sullivan, V. J., & Loew, R. C. (1998). Cultural and linguistic barriers to mental health service access: the deaf consumer's perspective. *Am J Psychiatry, 155*(7), 982-984.

Stewart, D., Freeman, M., Law, M., Healy, H., Burke-Gaffney, J., Forhan, M., . . . Guenther, S. (2006). Transition to adulthood for youth with disabilities: Evidence from the literature. *International encyclopedia of disabilities*.

Strauss, G. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. London: Wiedenfield and Nicholson.

Svirsky, M., Robbins, A., Kirk, K., Pisoni, D., & Miyamoto, R. (2000). Language Development in Profoundly Deaf Children with Cochlear Implants. *Psychological Science, 11*(2), 153-158.

Thew, D., Smith, S. R., Chang, C., & Starr, M. (2012). The deaf strong hospital program: a model of diversity and inclusion training for first-year medical students. *Academic Medicine, 87*(11), 1496-1500.

Thill, C. (2015). Listening for policy change: how the voices of disabled people shaped Australia's National Disability Insurance Scheme. *Disability & Society, 30*(1), 15-28.

Turley, P. K. (2015). Evolution of esthetic considerations in orthodontics. *American Journal of Orthodontics & Dentofacial Orthopedics, 148*(3), 374-379.

Ubido, J., Huntington, J., & Warburton, D. (2002). Inequalities in access to healthcare faced by women who are deaf. *Health Soc Care Community, 10*(4), 247-253.

Vichayanrat, T., & Kositpumivate, W. (2014). Oral health conditions and behaviors among hearing impaired and normal hearing college students at Ratchasuda College, Nakhon Pathom, Thailand. *The South East Journal of Tropical Medicine and Public Health, 45*(5), 1228-1235.

Watt, R. (2012). Social determinants of oral health inequalities: implications for action. *Community Dent Oral Epidemiol, 40 Suppl 2*, 44-48.

Wei, H., Wang, Y. L., Cong, X. N., Tang, W. Q., & Wei, P. M. (2012). Survey and analysis of dental caries in students at a deaf-mute high school. *Research in Developmental Disabilities, 33*(4), 1279-1286.

WFD. (2015). Sign Language. Retrieved from http://wfdeaf.org/human-rights/crpd/sign-language

WHO. (2011). Understanding Disability. *World report on disability.* Retrieved from http://www.who.int/disabilities/world_report/2011/chapter1.pdf?ua=1

WHO. (2015). Deafness and hearing loss. Retrieved from http://www.who.int/mediacentre/factsheets/fs300/en/

Witte, T. N., & Kuzel, A. J. (2000). Elderly deaf patients' health care experiences. *J Am Board Fam Pract, 13*(1), 17-22.

Wood, B. (2002). Caring for a limited-English proficient patient. *Association of Operating Room Nurs, 75*(2), 305-308.

Woodcock, K., & Pole, J. D. (2007). Health profile of deaf Canadians: analysis of the Canada Community Health Survey. *Can Fam Physician, 53*(12), 2140-2141.

Woodward, J. (1972). Implications for sociolinguistics research among the deaf,. *Sign Language Studies, 1*, 1-7.

Yalnizyan, A., & Aslanyan, G. (2011). Putting our money where our mouth is: the future of dental care in Canada: Canada Centre for Policy Alternative.

Yoon, P. J. (2011). Pediatric cochlear implantation. *Current Opinion in Pediatrics, 23*(3), 346-350.

Young, & Hunt. (2011). *Research with d/Deaf people*. Retrieved from

Zajadacz, A. (2015). Evolution of models of disability as a basis for further policy changes in accessible tourism. *Journal of Tourism Futures, 1*(3), 189-202.

Zazove, P., Niemann, L. C., Gorenflo, D. W., Carmack, C., Mehr, D., Coyne, J. C., & Antonucci, T. (1993). The health status and health care utilization of deaf and hard-of-hearing persons. *Arch Fam Med, 2*(7), 745-752.

Zhang, W. (2008). Oral health service needs and barriers for Chinese migrants in the Wellington area. *N Z Dent J, 104*(3), 78-83.

Appendix A. Interview Guide

1) I would like to begin by asking what sorts of dental problems did you have in the past and what did you do about it?

How often do you usually consult a dentist and for what purpose?

2) Can you describe dental visit(s) in detail?
How did you find a dentist?
Did any dentist refuse you treatment?
Did you have any problems in obtaining appointments?
Did you have an emergency contact for the dentist?
For each situation, could you describe what treatment plan was suggested to you?
Did the dentist describe you the plan in detail?
What factors made you accept or reject the treatment plan?
How many visits did it require to complete the treatment?
Did you complete the treatment? Were you satisfied with the treatment?
How does your experiences influence your decision to consult dentists in future?

3) Communication
Did someone (family member or sign language interpreter) accompany you to the visit?
Did you have any difficulties during the process of dental treatment?
Can you highlight details of these difficulties? Did your dentist clearly explained you the treatment?

4) What are the things that make it easy for you to find a dentist and obtain care?
How would you want your dentist to take care of you?
What can improve dental care accessibility for you?

5) Interpretation
If you compare the dental services with other healthcare, you have received. Are there any similarities or differences?
Who pays for dental interpreter services? Is requesting interpretation service any different in dental care from other aspects of life?

6) Miscellaneous
How do you take care of your teeth?
What is the importance of teeth in your everyday life?
Are you taking any regular medications for other health conditions?

Appendix B: Demographic Questionnaire

PLEASE TELL US A LITTLE ABOUT YOU

1. You are a _____ Man _____ Woman. **2.** Your age: _____ years old

3. You are ____ Single ____ Widowed

____ Married ____ Divorced

4. You are	**5.** You have a
____ Deaf (part of Deaf culture)	____ profound hearing loss (over 90dB)
____ deaf (not part of Deaf culture)	____ severe hearing loss (71 -90dB)
____ Hard of Hearing	____ moderate-severe hearing loss (56-70dB)
____ Late deafened adult	____ moderate hearing loss (56-70 dB)
	(in your best ear)

6. When did you become Deaf or Hard of Hearing?

_____ born deaf or hard of hearing OR Age became deaf/hh: _____

7. How do you communicate with . . . . (check all communication you use):

	Family	Dentists	Friends	Other health workers
ASL				
PSE/Signed English				
Gesture				
Home signs				
Interpreter				
Write notes				
Speech				
Lip-reading				

8. What is your BEST language? ___ ASL ___ English ____ Other:____________________

9. What is your FAVORITE way to communicate ? ____ Sign Language ____ Write/Read notes
___ Speech/Lip reading ____ Interpreter ____ Other: ____________________________

10. Where do you get your dental insurance from?

____ through my work

____ through my wife/husband's work

____ through my family's work

____ I am retired, but, through my former work

____ no dental insurance

____ Medicare

11. Your family's annual income: $___________

12. Your highest education level you finished:

____ did not finish high school
____ high school
____ some college education
____ AA or AS degree
____ BA or BS degree
____ MA or MS degree
____ Ph.D. degree

(Source: J Gen Intern Med. Mar 2006; 21(3): 260–266)

Appendix C: Research Consent Form

Date____________

Title of Research: Access to and Utilization of Dental Services by the Deaf and Hard-of-Hearing population in Montreal: A Participatory Research Study

Student Researcher: Fahad Siddiqui, Division of Oral Health & Society, Faculty of Dentistry, McGill University, Tel: (514) 449 8773, Email: fahad.siddiqui@mail.mcgill.ca

Academic Supervisors: Christophe Bedos, PhD and Mary Ellen Macdonald, PhD, Division of Oral Health & Society, Faculty of Dentistry, McGill University, Tel: (514) 398 7203 Ext. 0129, Email: christophe.bedos1@mcgill.ca and mary.macdonald@mcgill.ca

Introduction

We are requesting your participation in our research project which is aimed at understanding and improving dental services for the Deaf and Hard-of-Hearing communities in Montreal. Kindly take a moment to go through the details of this research project before deciding if you would like to participate in this project.

This consent form will provide you with details of the aims of this study, procedures, benefits, risks and any inconvenience related to your participation. Furthermore, we will also provide you the contact details of people that you may have to contact, if necessary.

In case there are any words or information that you do not understand, please feel free to ask us for complete clarification.

Purpose of the Research

There is little knowledge in the field of research regarding the dental care of people who are Deaf and Hard-of-Hearing. Much of what exists indicates that dental health of this community is not ideal. Therefore through this qualitative research study we hope to highlight any problems the community is experiencing as well as to plan and implement solutions to improve dental services of the Deaf and Hard-of-Hearing communities in Montreal.

This research project involves interviewing participants regarding their experiences of dental care. We plan to interview at least 10 Deaf and 10 Hard-of-Hearing individuals.

For this project we will work together as a team with representatives of Deaf and Hard-of-Hearing community, dentists and policy makers. This team will advise us at different stages of research. For example: when we share the results of this study to a Deaf audience, we will seek advice from a Deaf person on our team as to how to best communicate with Deaf people.

We anticipate that this research project will take place over a period of one year. Starting approximately in January 2015 and ending in December 2015.

Nature and duration of participation

If you agree to participate, your participation will involve an interview of up to one hour duration. With your permission, the interview will be audio and/or video recorded. This recording will be destroyed once it is written as a text file.

Personal benefits from participating in the research study

There are no personal benefits for you from participating in this research study. However your contribution will help us to improve dental services for the Deaf and Hard-of-Hearing communities in Montreal. Furthermore, your contribution will also help in the advancement of scientific research for this population.

Risks associated with participating in the research study

There is no expected discomfort or risk involved in participation. You may choose to decline to answer any question or to withdraw from this study at any time by contacting us.

Inconveniences associated with participating in the research study

There is little inconvenience expected regarding your participation. We are flexible with interview date, venue and timing. We will also provide a Sign Language interpreter of your choice (ASL or LSQ) if desired.

Access to subject's medical chart

N/A

Confidentiality

Only the researchers will have access to any identifiable data. This data will be stored in the student researcher's computer in a locked office at McGill University, in password protected files and folders. All data related to your participation will be made anonymous; that means you will not be identifiable in any publications or reports. This pledge of confidentiality also means that the interview materials will be coded and stored in such a manner that will make it impossible to identify them directly with any individual. This data will be stored for seven years after the end of the research project. Also note that a person appointed by the Research Ethics Board (REB) could have access to the data for monitoring purposes.

Questions concerning the study

If you have any questions related to your participation in this study and about the research project overall, we will be happy to address them.

Voluntary participation and withdrawal of the participation of the subject

Your participation in this research study is completely voluntary. It is understood that you have a right to withdraw from this study at any time you wish. Please note that your withdrawal from the study will not affect any services to which you are currently entitled. Furthermore, if desired all data related to your participation can be destroyed.

Responsibility clause

While agreeing to participate in this study, please understand that you are not giving up any of your legal rights nor release the researchers, sponsors or institutions involved of their legal and professional obligations

Compensatory indemnity

Your participation in this research project is completely voluntary and you will not be provided with any financial or any other compensation for your participation.

Contact persons

If you have questions regarding the study, want to report an unfavourable incident or point out your withdrawal from the study. You may contact Fahad Siddiqui, Student Researcher at the Faculty of Dentistry, McGill University by email: fahad.siddiqui@mail.mcgill.ca

If you have any questions about your rights and recourse or your participation in this research study, you can contact Me Anik Nolet, Research Ethics coordinator for the CRIR'S Institutions at (514) 527-4527 extension 2649 or by e-mail anolet.crir@ssss.gouv.qc.ca

Conclusion

Please be assured that you can take the time required to read this document and ask further questions.

Consent

I state that I have read this consent form. I understand this study, the nature and extent of my participation, as well as the benefits and risks/inconveniences to which I will be exposed as presented in this form. I have been given the opportunity to ask questions concerning any aspects of the study and have received answers to my satisfaction.

I, the undersigned, voluntary agree to take part in this study. I can withdraw from the study at any time without prejudice of any kind. I certify that I have had sufficient time to consider my decision to participate in this study.

A signed copy of this consent form will be given to me.

NAME OF PARTICIPANT (print)	SIGNATURE OF PARTICIPANT
____________________________	__________________________

Signed at __________________________ , the ___________, 20___.

Sign Language Interpreter Consent

I, the undersigned, agree to be audio and/or video recorded during interpretation of interviews.

NAME OF INTERPRETER (print)	SIGNATURE OF INTERPRETER
___________________________	___________________________

Signed at __________________________ , the ___________, 20___.

Responsibility of the Student Researcher

I, the undersigned, ________________________________, certify
(print)

(a) having explained to the research participant the terms of this form
(b) having answered all the questions he/she as asked in this regard
(c) having clearly indicated that he/she remains free, at any time, to end his/her participation in the above described research study
(d) that I will give him/her a signed and dated copy of this form.

Signature of the Student Researcher

Signed at __________________, the ______________ 20___.

CRIR
Centre de recherche
interdisciplinaire
en réadaptation
du Montréal métropolitain

Appendix D: Formulaire de consentment

Date ___________

Titre de la recherche: Accès aux soins buccodentaires des personnes sourdes et malentendantes de Montréal: une recherche participative.

Étudiant conduisant la recherche: Fahad Siddiqui, Unité de recherche sur la santé buccodentaire et la société, Faculté de médecine dentaire, Université McGill, Tél: (514) 449 8773, Courriel: fahad.siddiqui@mail.mcgill.ca

Superviseurs de l'étudiant: Christophe Bedos, PhD et Mary Ellen Macdonald, PhD, Division santé buccodentaire et société, Faculté de médecine dentaire, Université McGill, Tél: (514) 398 7203 Ext. 0129, Courriel:christophe.bedos1@mcgill.ca et mary.macdonald@mcgill.ca

---

Introduction

Nous vous invitons à participer à notre projet de recherche. Notre but est d'améliorer l'accès aux soins buccodentaires pour les personnes sourdes et malentendantes de la région de Montréal. Veuillez prendre le temps de lire tous les détails de cette étude avant de prendre une décision. Ce formulaire de consentement vous fournira des explications concernant votre participation à l'étude : il en décrira les procédures et présentera les bienfaits de votre participation ainsi que les risques et les inconvénients. De plus, ce document vous fournira des informations nécessaires pour contacter des personnes qui pourront vous apporter plus d'informations si vous le souhaitez.

Enfin, si vous ne comprenez pas certains mots ou certaines informations dans ce document, nous serons heureux de vous aider à les clarifier.

Le but de l'étude

Peu de recherches ont été conduites dans le domaine de l'accès aux soins dentaires pour les personnes sourdes et malentendantes. Nous souhaitons combler cette lacune et mieux comprendre les problèmes rencontrés par cette communauté à Montréal; nous désirons aussi développer des solutions pour améliorer la qualité des services dentaires qui leur sont offerts. Cette recherche consiste à interviewer des personnes sourdes ou malentendantes. Nous prévoyons rencontrer 10 personnes sourdes et 10 personnes malentendantes.

Pour ce projet nous travaillerons en partenariat avec des personnes qui représentent la communauté des personnes sourdes et malentendantes ainsi qu'avec des dentistes et des décideurs politiques. Cette équipe nous conseillera à différentes étapes de la recherche. Par exemple, l'équipe pourra nous conseiller sur la meilleure façon pour les dentistes de communiquer avec les personnes sourdes et malentendantes.

Nous prévoyons que ce projet de recherche va durer un an. Nous comptons commencer en janvier 2015 pour achever en décembre 2015.

Durée et type de participation

Si vous acceptez de participer, vous serez interviewé pendant environ une heure. Le but de cette entrevue sera de discuter de vos expériences reliées aux services dentaires à Montréal. Cette entrevue se déroulera dans un endroit qui vous conviendra (par exemple un café, votre domicile, un centre communautaire comme le Centre Mackay, ou encore mon bureau). Avec votre permission l'entrevue sera enregistrée de manière audio et/ou vidéo. Cet enregistrement sera détruit lorsqu'il sera transcrit. De plus, avec votre permission et celle de votre dentiste, nous vous accompagnerons possiblement lors d'une visite dentaire. Cela nous permettra d'observer votre rencontre avec des professionnels dentaires et de mieux savoir à quels types de problèmes vous pourriez faire face. Notre accompagnement lors de cette consultation, toutefois, est facultatif.

Avantages prévus pour le participant

Rien ne garantit que vous puissiez retirer des avantages personnels de votre participation à cette étude. Cependant, votre participation pourrait nous aider à améliorer les services dentaires offerts à la communauté des personnes sourdes et malentendantes de Montréal. De plus, votre participation pourrait nous aider à faire progresser les connaissances dans ce domaine.

Risques et complications

Il n'y a pas d'inconforts ou de risques prévus en participant à cette étude. Vous pouvez refuser de répondre à n'importe quelle question; vous pouvez aussi vous retirer en tout temps du projet.

Inconvénients

Il n'y a pas d'inconvénients prévus en participant à cette étude. Nous sommes flexibles concernant la date et l'heure de la rencontre ainsi que de l'endroit. Nous vous fournirons également un interprète pour la langue des signes de votre choix (ASL ou LSQ) si vous le souhaitez.

Accès au dossier médical

N/A

Confidentialité

Votre participation à cette recherche est tout à fait confidentielle. Les chercheurs seront les seuls à avoir accès à des informations qui pourraient vous identifier. Ces informations seront conservées dans l'ordinateur de l'étudiant de recherche dans un bureau fermé à clé à l'Université McGill. Ces informations seront également protégées par un mot de passe. Toute information concernant votre participation à l'étude demeurera anonyme et ne sera jamais dévoilée lors des publications de recherche. Cette promesse de confidentialité signifie également que toute la documentation des entrevues sera codée et entreposée de façon à ce qu'il soit impossible de vous identifier. Cette documentation sera conservée pendant 7 années après la fin du projet. Il faut noter qu'il est possible que la personne responsable du Comité d'éthique de recherche puisse avoir accès à vos informations pour vérifier la documentation.

Questions concernant la recherche

Il nous fera plaisir de répondre à toutes vos questions concernant cette recherche.

Participation volontaire

Votre participation à cette recherche est entièrement volontaire. Il est entendu que vous pouvez vous retirer de la recherche à n'importe quel moment. A noter que votre retrait de l'étude n'affectera pas les services auxquels vous pourriez avoir droit. Dans le cas où vous decideriez de vous retirer de l'étude, vos données seraient détruites et aucun usage n'en serait fait, ni pour la recherche, ni pour autre chose.

Responsabilité

En acceptant de participer à cette étude vous ne renoncez pas à vos droits légaux; de même, votre participation ne délivre pas les chercheurs, sponsors, ou institutions impliqués de leurs obligations légales et professionnelles.

Compensation

Votre participation à cette recherche est entièrement volontaire et vous ne recevrez pas de compensation financière ou matérielle.

Contacts

Si vous avez des questions concernant l'étude, si vous voulez rapporter un incident désagréable, ou si vous souhaitez simplement vous retirer de l'étude, vous pouvez contacter Fahad Siddiqui, étudiant à la Faculté de médecine dentaire de l'Université McGill par courriel à l'adresse suivante : fahad.siddiqui@mail.mcgill.ca

Si vous avez des questions concernant vos droits et recours ou sur votre participation à l'étude, vous pouvez contacter Me Anik Nolet, coordinatrice en éthique de recherche pour le CRIR, au (514) 527-4527 poste 2649, ou par courriel à l'adresse suivante : anolet.crir@ssss.gouv.qc.ca

De plus, vous pouvez contacter l'institution où vous avez obtenu vos services pour faire part de vos commentaires ou préoccupations éventuels au sujet de cette étude.

Consentement

Je déclare que j'ai lu ce formulaire de consentement. J'ai pris connaissance de l'étude et de la nature de ma participation, de même que des bénéfices, risques et inconvénients liés à ma participation. On m'a donné la possibilité de poser toutes les questions que je souhaitais sur l'étude et j'ai obtenu des réponses satisfaisantes à celles-ci.

Je, soussigné, accepte de façon volontaire de participer à cette étude. Je peux me retirer à n'importe quel moment sans préjudice d'aucune sorte. Je certifie que j'ai eu suffisamment de temps pour réfléchir sur ma décision de participer à cette étude.

Une copie de ce formulaire de consentement me sera remise.

NOM DU PARTICIPANT (en caractères d'imprimerie) SIGNATURE DU PARTICIPANT

______________________________ ______________________________

Signé à ____________________________ , le _______________ 20___.

Consentement pour l'interprète de Langage des signes

Je soussigné, donne la permission pour être enregistré ou filmé pendant l'interprétation d'entretiens.

NOM D'INTERPRÈTE (en caractères d'imprimerie) SIGNATURE D'INTERPRÈTE

______________________________ ______________________________

Signé à ____________________________ , le _______________ 20___.

Responsabilité de l'étudiant de recherche

Je, soussigné, ___________________________________, certifie:
(en caractères d'imprimerie)

(a) avoir expliqué au participant les termes de ce formulaire.
(b) avoir répondu à toutes les questions concernant ce formulaire
(c) avoir clairement indiqué que le participant est libre, à n'importe quel moment, de terminer son engagement à cette étude.
(d) que je vais remettre à la personne participant une copie de ce formulaire signé et daté.

Signature de l'étudiant de recherche:

____

Signé ____________________