Between Struggle and Hope:
Understanding the Oral Care Experiences of Children Living with Autism Spectrum Disorder(ASD);
A Parent's Perspective

Amina Ali Abomriga
Faculty of Dentistry
McGill University
Montreal, Quebec, Canada
July 2017

A thesis submitted to McGill University in partial Fulfilment of the requirements of

the degree of Master of Science

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I am going on a journey,
Won't you come along?
I need someone to help me.
A person big and strong.

I'm walking on my journey
But my feet are very small.
Can you stand beside me,
And catch me if I fall?

At times when I can't keep up
With life and all its fears,
Can you put me on your shoulders
And wipe away the tears?

I promise when the road is tough
And you want to turn back home.
I will hold your hand real tight,
So you won't feel so alone.

I'm going on a journey
I don't know where it ends,
But if we walk together,
We can always be best friends.

And when the journey's over
And we find where we should be.
I know that you will be so glad,
You took this path with me.

I'm going on a journey,
Please, won't you come along?
I need someone to guide me
A parent—big & strong.

Written by Sally Meyer

http://www.child-autism-parent-cafe.com/I-am-going-on-a-journey.html

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DEDICATION

This thesis is dedicated to

My parents Ali and Atiga, and

To all the parents who are raising children living with ASD, for your spirit, hope, and unconditional endless love.

To my loving husband, Ahmad, for supporting me and for teaching me how to be tougher and persevere.

To **Asma, Arwa, Jumana, and Raghad**… you changed my life for the better and gave me reasons to continue. Your lovely smiles have inspired me more than you can know.

ACKNOWLEDGMENTS

First and foremost, all praise and heartfelt thanks be to Allah, who embraced me with his kindness and gave me with the reasons and endurance to persevere.

I also would like to acknowledge my country, **Libya**, for offering me a full scholarship and supporting me during this critical stage. Thank you to my colleagues at **Zliten Dental College** particularly **dr. Atea bin Aisha and dr. Ahmed Kdai** who supported me during my application to this Masters program.

Words cannot express the gratitude I feel toward to the **participant parents** who generously shared their stories and trusted me. You have taught me the real meaning of unconditional love. Your stories broadened my mind and showed me a previously hidden dimension of the oral care of children living with ASD. Thank you, **Catherine Ritch**, for your generous assistance during data collection stage.

All the thanks and love to my family, and a very special thank you to my loving husband, **Ahmad**. I am very grateful for your encouragement and generous support. My everlasting love goes to my **children**. Your lovely smiles have always inspired me to persevere and overcome the stress.

All my gratitude goes to my family in Libya for your support during my studies. I will always be thankful to my **mom** and **dad** for all their love and help throughout my Masters studies and beyond. I could never express to you how your encouragement and love have touched me and allowed me to overcome any challenges and continue my work. My sincere thanks go to **Rabea** and **Abdulmajeed** for being the first to support me in my studies in Dentistry. Thank you,

Mahmood, for all your care, your help and for always being there. Thank you, **Mokhtar, Osama, Salah and Fouad** for your endless support during my studies. Special thanks to **Somia, Hanan, Halima, Sana and Asmahan** for believing in me and supporting me. I also wish to thank my **mother-in-law** and **father-in-law** for all your prayers and encouragement during my studies. To my brothers-in-law, **Abdu-Alghani** and **Yousef,** I can not thank you enough for your all the support and help.

This dissertation could not have been done without the supportive guidance of my supervisor, **Dr**. **Richard Hovey**. Thanks for introducing me to qualitative research and for being patient with my questions as I transitioned toward being a researcher. Thank you for the hours of meetings, for listening, and for answering my last-minute questions. Thanks for all the books and email invitation to join the qualitative groups that greatly helped me learn how to approach Interpretative Phenomenology. Thanks, from the bottom of my heart for all your encouragement to put this dissertation into its final stage.

I would like to acknowledge **Dr. Christophe Bedos**, my co-supervisor, for answering all my questions and for encouraging me to continue with this project. My sincere thanks extend to Dr. **Jocelyne Feine** for all your productive comments and encouragement.

I would like to acknowledge all my colleagues at the Department of Oral Health for your continuing support. Thank you**, Mark, Haider, and Ninonska** for all your generous support during my initial steps in this project. Thank you, **Maria Palumbo**, for answering all my inquiries promptly. Thank you, **Martine Morris**, the first stones of this research have been built through your (key words) and rich expertise in research. I also would like to acknowledge **Dr. Mary Ellen** and **Crystal Noronha** for inviting me to present my work during the qualitative group meeting. My thanks extend to my colleagues and friends who offered their insightful perspectives during the reading course. Learning with you was challenging, insightful, and rigorous. All your opinions were valuable and helped me to put this thesis into its final form.

Thank you to my supportive friends, **Ahlam, Botina, Asma, Aisha, Fatema, Roqia, Amal, Entisar, Awatef, Hanan** and **Omar**, for all your support, help, and encouragement. I have learned more than you could suspect through my acquaintance with you. Special thanks to **Entisar, Amal, Jodie**, and **Nadine**, for offering me your generous feedback during the writing of this thesis.

Finally, to the **memory of my grandmother**, I wish I could tell you how much your prayers, love and reassurance during my study have put into me to continue (19..-2016)..Peace

ABSTRACT

The unique characteristics of children living with Autism Spectrum Disorder (ASD) can make it challenging for them to maintain their oral health. Children living with ASD may display unpredictable behaviours and communication patterns that act as barriers to receiving proper oral care. Many studies have explored the oral health, dental needs, and oral health management techniques of children with ASD worldwide (1, 2); however, very little is known about the oral health of children with ASD living in Canada (3). Therefore, this research aims to provide an in-depth exploration of the child oral care experiences and concerns of parents of children living with ASD A qualitative research approach was selected for this research because of its ability to provide a deeper understanding of experiences related to ASD and oral health (4). The researchers adopted an Interpretive Phenomenology Analysis (IPA) approach which explicitly illuminates the parent's experiences and concerns toward oral care in depth. Six parents of a child and/or adolescent with ASD were interviewed. The interpretation of their accounts revealed three broad findings in the care of their child's oral health, namely, "Oral care as a struggle", "struggling with(out) giving up" and "Oral care as a Hope", along with other subordinate themes. The experiences of parents or care providers raising a child with ASD offered valuable insights into the strategies they use to manage the oral health needs of their children. Parallel with the objectives of this study, the parents' narratives documented many barriers that complicated the oral care experience of their children. The first-hand knowledge and understanding their stories reveal have the potential to inform clinical knowledge and practice, specifically in terms of treatment approaches that are most effective. This research will help inform the development of

a coherent and adaptive health system that is responsive to the oral health needs of children with ASD and to achieve better Oral Health Related Quality of Life (OHRQL) for those children.

Résumé

Les caractéristiques uniques des enfants vivant avec le trouble du spectre autistique (TSA) peuvent rendre difficile le maintien de leur santé bucco-dentaire. Les enfants vivant avec un TSA peuvent avoir des comportements imprévisibles et des modèles de communication qui constituent des obstacles pour recevoir les soins bucco-dentaires appropriés. De nombreuses études ont exploré la santé bucco-dentaire, les besoins dentaires et les techniques de gestion de la santé bucco-dentaire auprès des enfants atteints de TSA de par le monde (1, 2). Cependant, on en sait très peu sur la santé bucco-dentaire des enfants atteints de TSA vivant au Canada (3). Par conséquent, cette recherche vise à explorer en profondeur les expériences de soins bucco-dentaires chez les enfants atteints de TSA et les préoccupations de leurs parents. Une approche de recherche qualitative a été choisie pour cette recherche en raison de sa capacité de dévoiler en profondeur les expériences liées aux TSA et la santé bucco-dentaire (4). Les chercheurs ont adopté une approche d’analyse phénoménologique interprétative (API) qui illumine explicitement les expériences et les préoccupations des parents en matière de santé bucco-dentaire en profondeur. Six parents d’enfant et/ou d'adolescent atteint de TSA ont été interviewés. L'interprétation de leurs récits a révélé trois grands thèmes dans leurs expériences dans le soin de la santé bucco-dentaire de leur enfant, à savoir «Les soins bucco-dentaires sont une lutte», «La lutte contre l‘abandon » et « Les soins oraux comme espoir », ainsi que d'autres thèmes.subalternes.

Les expériences des parents ou des fournisseurs de soins qui élèvent un enfant atteint de TSA ont révélé des idées précieuses en ce qui concerne les stratégies qu'ils utilisent pour gérer les besoins

en santé bucco-dentaire de leurs enfants. Parallèlement aux objectifs de cette étude, les récits des parents ont documenté de nombreux obstacles qui ont compliqué l'expérience de leurs enfants en matière de soins bucco-dentaires. La connaissance de première main et le fait de comprendre leurs histoires pourra contribuer aux connaissances cliniques et à la pratique clinique, en particulier en termes d'approches de traitement plus efficaces. Cette recherche aidera à mettre au point un système de santé cohérent et adapté qui répond aux besoins en santé bucco-dentaire des enfants atteints de TSA et qui permettra d’améliorer la qualité de vie en matière de santé bucco-dentaire (OHRQL) de ces enfants.

PREFACE AND CONTRIBUTION

The student was responsible for the whole process of this thesis writing. Dr. Richard Hovey was the supervisory investigator of this project and involved along all the stages of this study. After The student prepared the literature review, research proposal and the consent form. She submitted all the material and obtained the ethical approval for the study in September 2015. The candidate ran all the field work: she collected data, prepared the recruitment material and visited and contacted many non-profit organizations and community centers to announce about the study. Everything has been done under guidance of Dr. Hovey. The candidate transcribed all the interview except for two interviews that has been transcribed by another professional transcriber who works in this carrier.

DEFINITIONS OF STUDY’S MAJOR

Oral care: It is the processes that are involved to maintain the teeth, tongue and gum healthy. It includes both the oral hygiene at home and any other dental procedures at the dental office or the hospital.

Parent(s): It refers to the primary caregiver of the child. It includes the biological parents, relatives and/or foster parents.

Dental Clinic: it refers to the place where the professional dental car took place It includes both public and private dental clinics.

1 CHAPTER I: INTRODUCTION

*"Probably one of the reasons why I sort of wanted to participate in the study, because I was disturbed by a remark that the nurse there had made [ ]. One of the first things when I went (to the Children hospital dental clinic), her response was: If you are a good mother, you will brush his teeth!" (*Participant 2015)

These were the first words of one of the parents who participated in my interviews. After many years, this story was still affecting her. Then, it was clear how at ease she felt after telling her story. As she spoke, she brought me back to the time when I was practicing dentistry and perhaps saying the same kinds of things that this experienced nurse had said, thus giving me a lesson on how important it is to listen. After that, the other participant parents' accounts were replete with precious hidden meanings. However, while recounting the oral care experiences of their children who live with ASD, most of them described it explicitly as a difficult process. Each parent had his or her own story; however, the main feature of their experiences with their children's oral care was the oscillation (the dance) between struggle and hope.

This project begins with a literature review, in which I shed some light on the existing literature about the oral care experiences of children with ASD. In line with my research objectives, the literature review will cover issues of accessibility and barriers for oral care for children living with ASD. Following that, the findings section will document my interpretations.

1.1 Personal background and importance of the research

Understanding the oral care experiences of children with ASD is a crucial first step in initiating the proper steps in the maintenance of better oral health. My work in dentistry for children began when I was working in a public dental clinic in my home country of Libya, where I was assigned as a General Dentist to provide prophylaxis and basic dental services. I have always been passionate about treating children, and always dreamed of helping children to have better oral health through the promotion of preventive measures. Seeing children at the clinic for prophylactic visits was very satisfying for me. However, my work was not always easy. At times, I would see children visiting the clinic for dental emergencies, and children with ASD, in particular, would routinely visit the clinic for such emergencies. Unfortunately, we were unable to address the oral health needs of most of them under local anaesthesia. Many of them showed uncooperative behavior and were referred to be treated under General Anaesthesia(GA). The experience of examining a child with ASD for the first time was extremely moving for me. At that point, my passion for helping children to receive better oral care in general moved towards oral care for Children with Special Health Care Needs (CSHCN), and children with ASD.

Every time a child with ASD visited the clinic, new questions were raised. Are parents familiar enough with the practices of oral care at home? Why would they have postponed the dental visit? What measures were successful with their child? What were their concerns? As a dentist, I was always eager to ask about and understand their situation, yet I was never fully able to. The crowded clinic, the shortage of time, and the frustration of the child, made it even harder to ask and listen.

After I became a mother and I became more familiar with the difficulties associated with parenting, I came to a better understanding of what I had seen in the clinic. While I did not face major problems in terms of the oral care of my children, with all of life's daily stresses, I too realized that sometimes I needed to give up and skip tooth brushing for one night, which I would have considered to be non-negotiable in the past. Mothering has opened more windows from which to approach my work in children's dentistry, and to recognize with deeper empathy the hidden ordeal that is involved in the oral care of children with difficult behaviour. I began to carefully consider how this beautiful event of becoming a mother had changed my way of living, thinking, and working.

It was my passion to help improve the oral care of children with CSHCN that led me to choose it as my thesis project and guided me along this path. Becoming an interpreter researcher has been an interesting, inspiring, and rewarding journey. The narratives I heard and the interpretation of them have taught me invaluable lessons both personally and professionally. However, this research also demanded that I walk with philosophers like Husserl and Van Manen to learn how to listen, understand, and interpret the hidden meanings interwoven into the participants' words. Through those philosophers, I have learned how to see the invisible meanings through the participants' own eyes. Learning to see things through the participants' perspectives taught me to be more attentive and open to hearing untold layers of meanings within their experiences.

1.2 Research question:

This study has aimed to explore the oral care experiences of parents and their children living with ASD to learn first-hand how they attend to oral health practices at home as well as at the dental office. Through the research, a better understanding of the oral health experiences of parents with children living with ASD can be gained, with the further objective of offering clinicians and caregivers more information about these children's needs and thus enhancing their oral health practices at home and in the clinician-patient relationship. With this aim in mind, a qualitative research design has been adopted in order to answer the following question:

How do parents experience the oral care of their children who live with ASD?

1.3 Research Objectives

To identify how parents, maintain the oral care of their ASD children at home and what kinds of challenges exist in this regard

To identify how parents, deal with professional oral care services for their children, and what kinds of challenges exist

1.4 Research Significance.

Through this study, I intended to gain a better understanding of the oral health experiences of parents with children living with ASD with the further objective to offer clinicians and caregivers a more information about these children's needs and enhance oral health practices at home and within clinician-patient relationship.

By researching the parent's perspective about the oral health of their children, I intended to provide a first-hand knowledge which can be best utilized as an educational tool for oral health professionals, students and patient / guardians through establishing workshops and continuing studies programs using appropriate knowledge translation and transfer methods.

I propose that effective oral health can enhance the overall quality of life for people that can be raised by applying new policies and practices that can reduce challenges and limitations faced by children with ASD and their families through educational perspectives obtained through explicit recognition of oral health needs experienced by parents of children with ASD.

Furthermore, I envision that this study can be a catalysis for further research concerned about the nature and the level of the stress that parents of Intellectual Disabilities children might suffer. Hence, being able to establish a reasonable well-organized community program to help future parents of children with ASD to adapt and be more productive

2 CHAPTER II: LITERATURE REVIEW

2.1 Literature review for qualitative research

In many research designs, the literature review is written at the beginning of the research process. The tradition in phenomenological inquiry, however, encourages researchers to conduct the literature review after establishing the findings, thus allowing the researcher to be more attentive and open to the new opinions and concepts embedded within the participants' experiences (5). Following this tradition, I chose to write the literature review after I completed the data interpretation.

2.2 What is ASD

There are many ways to define ASD, but the most common are from the medical or social models. However, the medical description appears to be the most frequently used for ASD is the most commonly found one in the literature.(6) The advocates for social model to address ASD focus on reshaping the society, to accommodate the impairment, rather than interrupt, correct and rehabilitate the impairment.(7) In contrast, the medical model approach focuses on reshaping the impairment through preventing, treating and rehabilitating the condition it self. I believe that both models are important to help the individuals who lives with disabilities to enjoy a better Health Related Quality of Life (HRQL). Much of the literature concerned with the oral health of individuals who live with ASD adopted the medical model to address disabilities to communicate and describe ASD. For this reason, I adopted the medical model's definition for ASD for consistency, readability and enhanced understanding in this chapter. The medical model defines Autism Spectrum Disorder (ASD) as a neurodevelopmental disorder characterized by impairment in verbal and nonverbal communication and fundamental problems in social interaction. Also, all individuals who live with ASD engage in repetitive, stereotypical behaviours or interests.

Since its detection by Leo Kanner in 1943 (8), and because of its heterogeneous clinical presentation, ASD classification has witnessed a remarkable development. In 2013, the American Psychiatric Association published the most recent diagnostic criteria for ASD (9). This version includes a fundamental change to the diagnostic criteria that was released in 2000 (10, 11). The new definition eliminates the previous individual categorizations of ASD, including autistic disorder (AD); childhood disintegrative disorder (CDD); Asperger's disorder (AD); Rett syndrome (RTT); and pervasive developmental disorder not otherwise specified (PDD-NOS), and encompasses them all under Autism Spectrum Disorder. The usual thee diagnostic criteria, which previously involved impaired communication skills, impaired social skills, and engagement in repetitive stereotypical behaviour, have been collapsed into two criteria instead, with impaired communication and social skills being treated as a single criterion". The required number of symptoms for each criteria has also been altered (11)

2.3 Diagnostic criteria

Under the former the DSM-IV, a child should demonstrate at least six of twelve deficits in social interaction, communication or repetitive behaviors. Under the DSM-5, a child should demonstrate three deficits in the category of social communication and at least two symptoms in the repetitive restrictive behavior category. In addition to the former two categories, the DSM-5 states that the child must meet extra two criteria to be diagnosed with ASD. Collectively, the following four criteria (from the Diagnostic and Statistical Manual of Mental Disorders: DSM-5, 2013):

Persistent deficits in social communication and social interaction across contexts meeting all of the following:

A. Social-emotional reciprocity (e.g., conversation, joint attention)
B. Nonverbal communicative behaviors (e.g., eye contact, body language, facial expressions, gestures)
C. Developing and maintaining relationships (e.g., imaginative play, making friends)
D. Restricted, repetitive patterns of behavior, interests, and activities meeting at least two of the following:
    a) Stereotyped/repetitive speech, motor movements, or use of objects.
    b) Excessive adherence to routines/rituals or excessive resistance to change.
    c) Highly restricted fixated interests, abnormal in intensity or focus.
    d) Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment
E. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)
F. Symptoms together limit and impair everyday functioning, with three levels of severity:
    - Requiring support (Mild)
    - Requiring substantial support (Moderate)
    - Requiring very substantial support (High)

2.4 Oral health for children living with ASD

The unique characteristics of children living with Autism Spectrum Disorder ASD can make it challenging for the maintenance of their oral health. Children who live with ASD may display unpredictable behaviours and communication patterns that act as barriers for them to receive proper oral care. Many aspects of the oral health of children with ASD have been investigated worldwide(12-14). Most studies have explored the oral health status,(15, 16) the unmet dental needs(17, 18), and the dental management strategies for children with ASD(19-21). Some studies, although very few, shed more light on the barriers children with ASD experience to getting good oral care.(12, 22-24) In line with the objectives of this study, I focused my literature review on research that examined the challenges of oral care for children with ASD.

2.5 Barriers to oral care for children living with ASD

My participants described many barriers that contributed to difficulties in getting good oral care for their ASD children both at home and at dental office. Although the topic of barriers to oral care is exploratory in nature, all the studies that explored this issue were quantitative, and primarily conducted in the USA. The most commonly described barriers were those that related to dental services, and very few studies have been concerned with oral care challenges at home.

Barriers that could interfere with access to oral care and that could complicate dental treatment interventions have been reported in the literature by both parents and dental care providers; however, parents were the main source of information in these studies. The barriers outlined were common throughout all the studies: barriers related to the child, barriers related to parents and caregivers, and factors related to dentists and the health care system (1)

2.5.1 Barriers related to the child

Parents of children with ASD have reported many barriers related to the child, primarily including behavioral issues and sensory dysfunction. Worldwide, several studies have found that factors related to the child himself/herself were the most commonly cited barriers (1, 3, 23, 25-28). Such factors include uncooperative behaviour, sensory dysfunction, and fear and lack of communication.

Child uncooperative behaviour has been cited by many studies as the primary barrier, from the perspective of both parents and dentists (23, 25, 26, 29). Dentists too have reported child uncooperative behaviour as the main barrier for them to provide dental services for children with disabilities. (30) In Canada, only one study has examined access to oral care for children with ASD in Toronto, and in this study, parents reported child behavior as a barrier. (3)This study showed that younger children were more uncooperative than older children, and the parents also cited their child's negative behaviour as the main reason behind their unmet dental needs.

Of the above mentioned studies, only one explored the triggers and the nature of the expected negative behaviour (25). Barry, O'Sulliva, Tou, (2014) found that strange tastes and smells, head touching, bright lights, and small enclosed spaces are potential triggers for unfavourable behavior (25). Barry et al., 2014 stated that child un-cooperative behaviour is mostly expressed as crying and lying on the ground. Also, the ASD child if developed negative behavior could also exhibit self-injurious behavior (SIB) or even attack others (25). Stein. Polido, Najera & Cermak, 2012Stein et al., 2014 have successfully correlated sensory dysfunction in children with ASD and uncooperative behavior during dental treatment. Their research found parents of ASD children with sensory over-responsivity faced more difficulties in dental office when compared with ASD children without sensory over-responsivity (65% vs. 39% respectively). (31) Moreover, parents of ASD children with sensory over-responsivity exhibited more uncooperative behaviour and even needed sedation or general anaesthesia for simple dental cleaning when compared with ASD children without sensory over-responsivity.

Fear and communication problems have been cited by fewer studies as a challenge (1, 3). ASD children experience high levels of anxiety and fear. (32, 33)In the Canadian study, found that 75% of the ASD children in the selected group had phobias and experienced fear during dental procedures, which is an immensely higher proportion than that found in other studies among children without ASD. (33) Communication problems are very common among ASD children, which has been found to complicate the oral care process. Gadi found that ASD children with poor on no communication are less cooperative and more likely to have their dental treatment done in a hospital setting.(3)

2.5.2 Barriers related to the parents

Many studies have shown that minor factors related to parents could have an impact on their ASD child's oral care experience, including education, marital status, age, and area of residence. It has been found that the education of the parents was positively related to the possibility of finding a dentist to treat their ASD child (3). Gadi, 2011 found that higher education of the parents correlated with the first dental visit of their child at an earlier age. Furthermore, it has been demonstrated that married couples are more likely to have private dental insurance that covers their ASD child's dental needs (3, 34). Another finding in Gadi's study showed that young married couples (less than 34 years old) who have children living with ASD are less likely to have private insurance, which could have an impact on the quality of oral care of their children. In addition, the residence area of the ASD child is a crucial factor in the accessibility of dental services. Two Canadian studies found that ASD children who live in urban areas has better access to oral care than those who live in rural areas.

2.5.3 Barriers related to the dentistry

Many studies have investigated the effect of the dental system on ASD children's oral care has been investigated. Several studies in the USA and one study in Sudan has shown that parents have both perceived and documented the cost of dental treatment as a barrier (1, 23, 26). For example, Lia et al. (2012) questioned parents about the challenges they experienced during oral care of their ASD child. Of these, 12% reported that their ASD children had unmet needs, 38% reported that they could not afford the cost of dental treatment, and 15% indicated that the lack of dental insurance was a major barrier.(23) In Canada, Gadi found that 21.4% of the recruited parents reported that they could not afford the cost of dental treatment and 24.3% found it difficult to meet the cost of the dental treatment for their ASD children (3).

Challenges related to the dental care provider have also been described. It is common for children with special health care needs and their families to face difficulties in finding a willing dentist (35) (2, 36). However, the refusal of the dentist was not a significant barrier for children with special health care needs in Ontario (37), where 89% of general dentists and 100% of pediatric dentists who participate in this study , from Ontario, have reported that they treat children with disabilities (38). However, different conditions fall under the category of "disability", and each has its own special characteristics that could affect accessibility to oral care in different ways (39, 40). In response, researchers began to examine access to dental care for ASD children in particular, considering the effects of their unique characteristics on accessibility. In the USA, parents of ASD children have reported finding a welling dentist as a barrier (29). In Canada on the other hand, Gadi et al., (2010) found that family structure and the caregivers' perceptions about the dentist's knowledge, regarding the ASD, had a greater impact on the accessibility of oral care for ASD children. However, more studies are needed to support this finding on different samples of ASD children (3).

Various studies have explored the factors behind dentists' willingness to treat children with ASD and other disabilities. In Taiwan, Tsai et al., (2007) have examined the reasons that could complicate the dentist's willingness to provide dental services for children with disabilities. (41)Three factors have been identified by the dentists as a precondition to treat disabled children: adequate academic training, adequate experience, and sufficient treatment time (41). The most important reasons cited for choosing not to treat disabled children were the inability to communicate with the disabled child or his/her family, the complexity of the treatment procedure, and the lack of the support from hospitals or clinics. In the USA, Similar findings have been reported by other authors who investigated the effects of education, among other factors, on the willingness and confidence of dentists and dental students to treat children with special health care needs (CSHCN). Casamassimo et al. (2004) have also reported that 30% of the dentists recruited from the ADA have cited lack of knowledge as a barrier, and those who treated children with disabilities more frequently perceived fewer barriers compared to the dentists who did not (30). Also, Wolff et al. (2004) explored dental students' perceptions toward their knowledge and confidence in treating people with retardation and found that more than 60% of the recruited dental students were not confident about providing dental care for people with retardation and more than 74% reported that they were not prepared to treat this type of patient (42). Interestingly, a more recent study has compared the attitudes of general dentists and pediatric dentists toward treating children with ASD, and assessed the relation between their dental education and their professional experience in treating children with ASD. (43) The authors found that pediatric dentists are about three "more likely to be willing to treat children with ASD than general dentists. (43) Also, dentists are more likely to treat children with ASD when they are more satisfied with their educational preparation.(43) Moreover, the proper use of a behavioral approach to these patients was proportional to the quality to their clinical education.(43) This study demonstrated the importance of dentists' knowledge and experience in relation to their willingness, confidence, and professionality in treating children with ASD (43).

Other factors such as transportation and waiting time have also been reported in the literature. Two studies, one from the USA, Lai, Milano, Robert and Hoope 2012. The other is from UK, Barry, Osullivan, and Toumba, 2014. Both studies have cited transportation as a challenge. In both studies, about 10% of the participant parents indicated that transportation to the dental clinic by car was or would be a barrier for their ASD child (23, 25). Unsurprisingly, a larger proportion of parents, about 41%, cited public transportation as a barrier and confirmed the importance of the availability of parking close to the dental clinic (25). However, a different study in the USA stated that transportation was not a significant barrier for the selected sample of parents (26). Regarding the waiting time, both Lia et al., 2012, and Barry et al., 2012 stated that parents in reported difficulties during waiting time. Lia et al., (2012) showed that more than 18% of the parents stated that setting up an appointment within the preferred timing was challenging. and 13.8% of them experienced difficulties due to the long waiting time in the waiting room of the clinic (23). The perceived difficulties associated with the waiting time have been reported in the qualitative part of Barry's study as well. (25) Interestingly, a higher number of parents than Lia's study felt that waiting time could be problematic; however, Barry et al., 2014 showed that will depend on many circumstances such as the waiting duration and waiting room size.(22)

2.6 Rational for the study

Many studies have explored the oral health status, the unmet dental needs, and the oral care experiences of children with ASD in the US and worldwide (16, 23, 44). For example, one such study explored the effects of ASD on children's oral care experience (44). As expected, the research showed that children with ASD faced significantly more challenges maintaining oral health at home and in the dental office as well compared to children who did not have ASD. More importantly, the study reported that families of children with ASD experience many barriers to accessing oral care in general.

In contrast, only one unpublished study regarding access to oral care for children with ASD has been done in Canada, in Toronto. This study utilized a survey approach to collect data through the Internet. The main finding reported that most of children with ASD in this sample had access to dental care. Moreover, this study stressed the importance of the parents' education and attitude toward dentist's capability in treating children with ASD. The qualitative questions in this study, although limited, outline briefly some of the health concerns of children with ASD in terms of access to oral care within the allocated sample.

Apart from the dental field, Tomlin et al., (2015) focused on the positive impact of qualitative research on the improvement of occupational therapy for children with ASD (45). They explained how occupational therapy practices and studies can be developed by incorporating important information which can only be obtained through qualitative studies.

Therefore, I have decided to study the oral care experience of children with ASD qualitatively. Such research will contribute to the field by providing a deeper understanding of the oral care experiences of children with ASD at home and at the dental clinic. This research thus has the potential to fill some of the gaps in the literature on the oral health of children with ASD in Canada.

2.6.1 Oral care experiences and challenges for children with ASD:

Stein, et al (2011) have explored the oral health experiences of children with ASD through surveys by their parents. The main goal of this study was to evaluate the oral care experiences of participants by examining the differences in the oral care experiences of children with ASD and those of their non-ASD peers. Stein and his group prepared a survey about children's dental care in order to collect information about oral health determinants from the parents' perspective. The survey was designed to estimate how autism affects the oral health care experience.

The researchers classified the oral health determinants into three categories: oral care at home, oral care at the dentist's office, and access to dental care. To examine oral care at home, they asked the parents about any difficulties they face during the daily oral hygiene routine and whether their children needed any help during the routine. They also inquired about the frequency of tooth brushing per week. The results were not surprising, as 71% of parents of children with ASD stated that they faced challenges in proper oral care for their children at home

(44). More importantly, about a quarter of the children with ASD needed assistance in cleaning their teeth at an older age (11-18 years old) and brushed less frequently than their typical (non-ASD) peers (44). Then, the parents were asked about their children's experiences at the dental clinic. Unlike their typically developing peers, children with ASD experienced significantly more difficulties during their dental appointment, with 52% of children with ASD experiencing problems versus 3% of typically developing ones (44). The parents of children with ASD further reported that their children were more sensitive to noise and light. Consequently, they were less cooperative during the dental appointment and some of them needed physical restraint or sedation for a simple dental cleaning (18% versus only 1% of the typically developing peers) (44). To spot any differences in terms of access to dental care, the survey asked about the number of dental prophylactic visits, and the parents' experiences in finding a dentist interested to provide this service. Surprisingly, the authors found that children with ASD had a comparable number of prophylactic dental visits when compared with the typically developing children. However, it was more difficult for parents of children with ASD to locate a trained dentist willing to treat their offspring. Unfortunately, about 25% of them stated that dentists refused to provide dental care to their children, while only 3% of parents of typically developing peers experienced the same problem (44). The above finding indicated that oral care for ASD children is complicated and requires more attention.

The results of this study showed that children with ASD face many barriers to the maintenance of proper oral health, such as finding a willing dentist. Also, the authors used a representative sample to address the research question, and there is consistency between the sample sizes recruited from both groups (ASD and typical) in terms of age, race, and parental education, which led a higher level of validity to the results. However, I suspect that the inclusion of children of a very young age (2-7) was unnecessary. This age group alone constituted 53% and 39% of ASD and typical groups respectively (44). Oral care experiences at this age, with or without ASD, are very limited and may significantly affect the study results. In addition, I argue that the demographic factor is very important and should have been included in the survey. This importance stems from the fact that people in different regions (urban or rural) have different rates of accessibility to dental services (46). Inclusion or exclusion of this factor may affect the outcomes of the study.

The oral care experiences of children in Canada is still an under-researched area. For the purpose of extending and enriching the research about the oral health of children with ASD, I have designed my project to focus on the oral care experiences of children with ASD. I chose to take a qualitative approach because of its potential to highlight deeper understandings of the experiences of ASD in relation to oral health. The framework of qualitative research will help to explicitly illuminate in depth the parent's experiences and concerns toward oral health while taking care of their children's well-being (47, 48).

2.6.2 Access to dental care for a selected group of children and adolescents with ASD

In Toronto, 70 parents who were attending "Geneva Centre" participated in a study that measured the barriers to oral care for children with ASD. Geneva Centre provides different services to children and adolescents with ASD and their families. This study aimed to identify the barriers to dental care for children with ASD by examining the correlation between three categories of variables: variables related to the dentist, variables related to the parents, and variables related to the child himself. Of the 70, 63 of the parents completed a net-based survey containing 49 multiple choice questions related to their children's dental history and accessibility to dental services. Additional questions related to the parents' social- demographic characteristics and their opinions about their children's oral condition. The researcher analysed the collected data using statistical tools and logistic regression. Regarding access to oral care, results indicated that children and adolescents with ASD in this population had access to dental care. Accessibility was affected by various factors, mainly parents' age and literacy level. With respect to oral health status, 34% of the participant parents reported that their child's oral health status was poor, and only 20% stated that it was very good. In addition, more than half of the parents said that their child's first dental visit was at 3 years-old or younger. According to the author, parents' understanding of the importance of early oral care was connected to the fact that most of them were highly educated.

In terms of access to dental care, parents' impression of the dental professional's familiarity with ASD was important to slightly more than a third of them; 40% stated that specialists in dentistry are not familiar enough with ASD. Regarding the effect of children's age on dental care accessibility, it was found that younger children with ASD showed more uncooperative behaviour and that access to dental care was more complicated compared to the older children with ASD.

In addition to this research, there were two other Canadian studies that examined the accessibility to oral care for children with developmental disabilities and/or children with special health are needs, including ASD. However, this study was the first study in Canada concerned specifically with the oral health of children and adolescent with ASD as a target group.

The author successfully determined the variables related to the accessibility to oral care. For example, considering parents' perceptions of dental professionals' familiarity with ASD reflected how this factor affected access to oral care; 40% of these guardians stated that specialist dentists are not familiar with ASD – an issue which has not been considered by other published research (22). Also, the inclusion of open-ended question was very effective, as such questions offer more flexibility to parents to express other barriers to accessing oral care.

However, the author himself admitted that the entire population of this study were highly educated and had private dental insurance. Consequently, the barriers to oral care among this population will be limited and non-reflective. For that, this research should be followed by other qualitative and quantitative studies in this area to overcome its limitations and provide more understanding of the oral care experiences of children with ASD.

2.6.3 Contribution of qualitative research to evidence in practice for people with ASD

Tomlin, George, & Swinth, 2015 have critically discussed the crucial role that qualitative research has played in improving occupational therapy for children with ASD (49) First, the authors illustrated the inherited weakness in quantitative research and its inability to independently fill the gap in the literature. Then, the author directly highlights the essential role of qualitative research to better understand the needs of children with ASD, and thus to identify the best practices to effectively improve the research about ASD occupational therapy.

The writer described the disadvantages of quantitative research in occupational therapy in detail. One of the inherent limitations of quantitative research is that it is best applied to typical people. These studies do not usually serve people with needs that deviate from the study's standard. Also, the generalizability is questionable in quantitative experiments as it is usually conducted under conditions which make its transferability into practice very difficult. In addition, statistical challenges do exist, such as the need for a large sample and difficulty generating comparisons with different diverse categories.

On the other hand, the author highlighted the importance of engaging qualitative research in occupational therapy research. One of the most important implications of qualitative research in any field is its flexibility to define the effects of different variables on a certain situation. By applying qualitative methodology, important issues from the patient's point of view are raised which could not otherwise be considered. Consequently, the qualitative research results can then be utilized by quantitative research to test and improve the treatment practices and achieve patient-centred care through evidence-based approaches. Therefore, the adoption of qualitative research is of a great value in health-related studies, and particularly those related to ASD.

Six studies have been presented as examples for the contribution of qualitative studies in occupational fields. One example of theses studies is "The socio-economic effects of ASD on family members (50). The results of this study, for example, will help provide valuable information to the field of occupational therapy to understand and modify their role in supporting these families', in this case by assisting them to return to their careers.

In fact, questions related to the validity and applications of qualitative research have always been raised. Tomlin et al., 2015 has answered and clarified the essential role of qualitative research currently. The authors have also presented many studies as examples, followed by explanation of the practical application for occupational therapy for children with ASD. Furthermore, these applications are, of course, transferable to other health sectors such as dentistry.

Qualitative research can play an essential role in dentistry, in particular, by providing an in-depth understanding of different oral health issues. In Canada, the oral health of children with ASD is one of the issues that has not yet been adequately researched. Thus, I have adopted a qualitative research approach to study the oral health experiences of children with ASD from parents' perspective. The experience of parents or care providers raising a child with ASD can offer valuable insight into the ways in which they have learned to manage the oral health needs of their children. This first-hand knowledge and understanding is of value not only to new parents of children living with ASD in determining how to provide them with optimum oral care, but also to oral health care providers in that it has the potential to inform their clinical knowledge and practice in their treatment of ASD children. This research will also contribute to the development of a coherent and adaptive health system that is responsive to the oral health needs of children with ASD, thereby achieving better Oral Health Related Quality of Life (OHRQL) for those children. To achieve this, we need to better understand the relationships of health care providers to patients and to parents. The co-creation of this kind of dialogue necessitates finding a common ground where parents and their children can communicate with health care providers through their experiences.

3 CHAPTER III: METHODOLOGY: INTERPRETATIVE PHENOMENOLOGY

The aim of this study is to gain an understanding of child oral care experiences among parents of ASD children. This study adopts a phenomenological framework through the use and analysis of semi-structured interviews. The following sections describe the research framework and methodology in more detail, including information on the procedure, participants, data collection and data analysis.

3.1 Interpretative Phenomenology: A philosophically based research approach

> "*We cannot understand without wanting to understand, that is, without wanting to let something be said...Understanding does not occur when we try to intercept what someone wants to say to us by claiming we already know it.*" Hans-Georg Gadamer

The research framework of the current study is interpretative phenomenology (IP). Phenomenology is a philosophical approach that evolved early in the 20th century. Phenomenology was described by Edmund Husserl, who was influenced by the work of philosophers including Rene Descartes, Immanuel Kant and Goerge Wilhelm Friedrich Hegel (51). Van Manen asserts that IP is a method of questioning and looking for potentialities around a question, rather than of targeting a concrete answer to the question (4, 51). Phenomenological inquiry involves the in-depth exploration and elucidation of the latent meaning within a certain essence of the phenomenon under study. (51) Phenomenology rests on a philosophical foundation, which makes phenomenological research deep, vivid and flexible. Sources like "Researching Lived experience" (4) offer further insight into this approach.

IP lays out the research approach that allows for the in-depth exploration of the lived experience of certain phenomena. (4, 52) Interestingly, IP has become very popular in health science research due to its utility in the exploration of the lived experiences of patients. (53, 54) Examples of research using IP include the exploration of the challenges of parenting a child with autism (55) and of parenting chronically mentally ill children through their lifespan (56). The book “Writing in the dark” (57) provides further examples of different lived experience studies. The IP approach is suited to the current study, as in order to gain an understanding of the experiences with child oral care of parents of children with ASD, it is important to explore their own words and perspectives. (58)

3.2 Research approach

The exploratory nature of this study determined the use of a qualitative research paradigm, Interpretative Phenomenology Analysis (IPA), which allows for an in-depth analysis of participants’ experiences, using a semi-structured interview. (4) IPA will help explicitly illuminate parents’ experiences with and concerns about their children’s oral care, as part of their caring for the well-being of a child with ASD.

In this study, I intended to explore the lived experience of parents of ASD children regarding the oral care of their children. The participant parent's accounts have grounded the understanding of how the oral care experiences of their ASD children looks like? (40) It also offered a deep insight toward the faced challenges encompassing the oral care of their ASD offspring. The exploratory nature of this study was consistent with the methodological traditions and applications of Interpretive Phenomenology (IP) approach (38, 47). For that, the Interpretive phenomenology (IP) approach has been adopted to capture, in depth, the oral care phenomenon of children who live with ASD from their parents’ perspective

3.3 Selecting research participants

In keeping with the phenomenological approach, participants were selected based on having the experience of taking care of the oral health of a child with ASD. The diagnosis of the children was confirmed by the parents. To be eligible for the study, parents had to be able to understand and complete the consent form and the interview in English.

3.3.1 Inclusion and exclusion criteria

The included parents should have a child who have previously diagnosed with ASD. Also, the child should be 10 years old or over to secure rich experience with oral care. Finally, the parents should have been able to comfortably read and speak in English. Exclusion criteria were: Parenting a child diagnosed with ASD under 10 years of age; Not being able to comfortably read and speak in English.

3.4 Research ethics considerations

After successful application of my proposed research project, the ethical approved has been offered in September 2015 by by Institutional Review Board (IRB) at McGill University. See appendix (c). The ethical approval has been extended in the subsequent year in August 2016 to allow for more interviews to be done. The invitation emails and flyers has been sent to three specific non-profit organizations concerned with Autism, including: Montreal Autism Center, Mariam Foundation and Autisme Montréal. Non-of the before mentioned institutions required to apply for another ethical approval. The invitation emails have been attached with a poster for the study, the ethical approval, covering letter explaining the study and the consent form. Once I have been contacted by the participant, I explained the study and the consent form. I made sure that they understand their rule during the interview, the expected interview duration. Before the interview, I explained the consent form and highlighted that they are not obliged to answer all the questions and they could withdraw at any moment. I also explained how their confidentiality will be respected and neither their names nor indicative personal information will be displayed, and pseudo names will be used during the transcription process. Finally, a Written informed consent has been signed by each participant before the interview took place (see Appendix B).

3.5 Conversation with the participant

Using the IP framework, the aim of the interviews was to obtain a rich and detailed experiential account of parents' experiences caring for their child's oral health. (51) It is less focused on opinions or personal perspectives than other interview forms. (51) Participant accounts in IP can be done through direct face to face interview or through written or recorded stories.

Before setting up the interviews, the consent form has been explained to the participant. All the parents have signed the consent form either directly before the interview took place or have sent by mail before the interview. I started Each interview with greeting the participant and introducing myself, as well as describing both my personal and professional motivations for conducting this research, which served to build a rapport between the me and the parent. The interviews were semi-structured, and therefore the researcher had a list of questions to guide the interview (see Appendix II). The conversations with each participant has offered me new insights and uncovered hidden aspects in their experience necessitating walking in a different path during the conversations. However, the question guide evolved over the course of the interviews to reflect the insights provided by the parents and allow the researcher to probe these aspects more deeply. I also developed and improved the questions guide through noting how the participant has responded to the question. Improving the question guide after each interview has resulted in gaining more detailed experiential data in the subsequent interviews. The researcher developed and modified the question guide after every conversation to continually improve the quality of information received. Interviews lasted between 30 and 90 minutes. In IP, the richness of the data is more important to analysis than the number of the interviews, and the information provided by the six interviews satisfied the requirement of understanding the oral care experiences of children living with ASD from their parents' perspective.(4, 51)

3.6 Data analysis

Data analysis in phenomenological inquiry does not require the researcher to follow specific steps or rules.(51) Van Manen describes phenomenology as more of a "method of questioning than answering". Therefore, it is possible to adopt many approaches to analyzing data in phenomenological research. For this reason, this chapter is titled "Methodology" rather than "Method" (59) (60), as unlike with the method, the methodology demands the researcher to remain open and reflective about the lived experience of the participants.(4)

Phenomenology rests on a profound philosophical foundation, which makes phenomenological research deep, vivid, and flexible. Therefore, the cohesive application of the approach's philosophy throughout the research process, starting with a clear phenomenological research question to the collection of quality experiential data that are consistent with phenomenological traditions, is the fundamental basis for establishing the data analysis.(51, 61, 62) Several specific steps were taken to analyse the data during the research process, which included audio listening and interview transcription, and reflective methods including transcript reading and writing. These strategies helped me gain insight into the lived experience of the interview subjects and uncover the hidden meanings of the researched phenomenon.

3.6.1 Audio recording and interview transcription

To analyse the text in phenomenological research, the researcher is encouraged to deeply engage with the narrated text in order to understand the meanings within the lived experiences shared by participants.(51) Interview transcription, as an introductory step in the analysis, enhanced my familiarity and in-depth involvement with the text. I refrained from using software at this stage to ensure and encourage myself to deeply engage with my participants' narratives.

I transcribed the interviews verbatim, except for some expression such as "kind of"" you know" and some word repetition because they complicated the reading and understanding of the text. I tried to recall and write notes about stances like pausing, change in voice tone, and strong facial expression, as these could be important during the interpretation process. For each interview transcribed, I made special notes about the interview process to avoid mistakes like unneeded interruptions and comments. I also developed and improved the question guide through noting how the participant responded to the questions. Improving the question guide after each interview resulted in gaining more detailed experiential data in subsequent interviews.

3.6.2 Reflective methods to develop findings

In phenomenology, the analysis process follows no specific rules, but it is a free and creative activity.(51) Van Manen invites researchers using PI to use various approaches to disclose the embodied meanings within the lived experience, in particular, through (a) reading and (b) writing. I utilized both strategies to interpret the text and extract the meanings of the lived experiences. The first step of the analysis (described above) involved transcribing the audio records through listening. I also read the transcripts over several times after transcription to ensure accuracy. At this stage, I initially tried to use software to code the text and simplify the analysis process. However, this approach failed to bring out the deep meaning of the texts or provide me with a deep understanding of the targeted phenomenon.

Instead, I adopted van Manen's recommended approach of performing a careful reading of the texts. Many ideas and points emerged from the data at this stage. I used different reading approaches, starting with a holistic reading of the text. During holistic reading, I read each interview transcript thoroughly as a whole. I at times read the texts out loud as this intensified my engagement with them. The holistic reading process enabled me to write a short text that briefly described each transcript. I was also able to identify the paragraphs most relevant to the targeted phenomenon. Because I avoided using software to code the text, I manually colour-coded the selected paragraphs and read them several times. I studied the selected paragraphs looking for related meanings. As suggested by Van Manen, I also utilized detailed reading. Detailed reading involves inspecting each sentence and word and referring to the etymological dictionary to grasp the original meanings of the words within the text. After the detailed reading, I extracted and highlighted some of the most relevant excerpts and key quotations which informed of the participants' experience. This process of holistic and detailed reading was repeated back and forth, as I developed new insights and became more confident in my reflections. Because interpretative phenomenology follows a circle moving from detailed to holistic and from holistic to detailed, I continued to engage with the texts in this way until no new insights emerged from my reflections on the participants' experiences. The holistic and detailed readings greatly facilitated my understanding of and reflection on the participant experience.

The holistic and detailed reading was accompanied by phenomenological reflection through writing, an essential element in the analytic process. PI requires an in-depth and thoughtful engagement with the lived experience of the participants to generate an in-depth reflective understanding.(4, 51, 63) The process of writing and selecting the appropriate words to write during the analysis stage opened profound insights and invited me to delve into my participants lived experiences. Hand in hand, reading and writing were the fundamental instruments of the analytic process. Insightful reading stimulated interpretative writing and deep reflection on my participants' experience.

3.6.3 Reflexivity

Reflexivity is defined as the evaluation or awareness of the effect of one's thoughts on the research process. (64) In phenomenology, reflexivity is an essential practice throughout the research process. Different philosophical approaches have different definitions of reflexivity. In descriptive phenomenology, Husserl believes that reflexivity demands that the researcher identify his own beliefs, thoughts, identity and biases and "bracket" them.(65) In interpretive phenomenology, the researcher's presuppositions are considered inevitable and are used to support the researcher's ability to understand the human experience. (66) The interpretive researcher aims to add his understanding to the participants' experiences, while preserving their perspectives as much as possible, in a process known as a "double hermeneutic." (64, 67)

Reflexivity in this project started before embarking the research process. It involved continuous thinking about my identity as a mother and a dentist. My sense of my own identity and my knowledge about oral care in children with ASD contributed to positioning my self-reflection throughout the research process. My self-reflection also involved me sharing my identity and my motivations for conducting this research with my participants and with the readers of my writing. Furthermore, seeking the perspectives of my supervisor and my peers during the interpretation process further enabled me to reflect on myself. Through self-reflection, I understand that my interpretation of the participants' experiences is only one interpretation and different researchers may have different interpretations and findings (4, 68).

4 CHAPTER IV: FINDINGS

"The truth of the man is not what he shows you, but what he can not show. So If you want to know, don not listen to what he says, but to what he does not "

Gibran Khalil Gibran

The participant parents offered rich accounts that revealed several possible findings. During the analysis, I needed to constantly remind myself of the research question to help keep my findings framed in accordance with it. After meticulous reading of the participant accounts, I found that the parents' experiences oscillated between "struggle" "and "hope". I noticed a tension and "inseparable" connection between struggle and hope and identified three main findings: "oral care as a Struggle" and "oral care as a hope".

4.1 Finding #1: Oral care as a struggle

Through their stories, the participants shared with me their oral health care experiences of their children living with Autism Spectrum Disorder(ASD) both at home and at the dental clinics. All the participants but one found keeping up with their child's oral health difficult and struggled to maintain the oral care of their children. According to the Oxford dictionary, |a struggle is "a determined effort under difficulties". Struggling as an experience is latent with suffering and hope. To suffer means to personally live with some degree of physical and / or psychological pain. The struggle has always been accompanied with a strong and endless desire to overcome the experience of "suffering". For these parents, the oral care of their children who live with ASD was often challenging at home and the dental office, or both. All the participant parents were eager from the beginning to recount their struggle with oral care. One of the parents described oral hygiene for their child at home as follows:

“*it is not easy but even if we are not fighting, but struggling with her to do it, we do it.*”

The connection between struggle and hope is explicitly expressed. The “friendship” between struggle and hope has thus been a distinctive feature of their experience.

The Etymology Dictionary suggests that the English word “struggle” is connected to the Dutch struikelen and the German straucheln, “to stumble” (online etymology dictionary) . To stumble is thus to lose balance. Parents may sense a loss of balance in their relationship with their children; the experience of struggle is the parent’s consciousness of having a relationship with their children unlike what they would expect or wish. The parent’s awareness of the “unexpected” relationship between themselves and their children, between self and other is, in itself, a struggle. Hegel stated that “the moment of difference arising when one is conscious of the “otherness” of other selves vis-à-vis oneself, and vice versa. Otherness and pure self-consciousness are mutually opposed moments in a “life and death struggle” for recognition.”(69). As perceived by the parents, the struggle was either related to child himself /herself, or related to the dental services. The lack of partner support was also a source for struggle for some parents.

4.1.1 The oral heath struggles

Although each experience was unique, the uncooperative behavior of the child has greatly affected and shaped the parents’ experiences of oral care for their children. For most of the parents, characteristics related to ASD were perceived as the main factor that has jeopardized the oral care process both at home and at the dental office. As described by the participants, ASD-related factors such as sensory dysfunction and communication problems were associated with the uncooperative behavior of their children during the oral care process. The parents reported that the oral care process sometimes triggered frustration and unpredictable behavior and body movements in children who live with ASD. Because of sensory dysfunction, the simple touch associated with teeth brushing could be experienced as very annoying to the child. However, the perceived struggle varies from one parent to another. When asked about their experiences with their children's oral care, the parents were divided into two groups. The first group, comprised of three participants, reported that maintaining oral health was an obstacle both at home and at the dental office. The second group, two participants, felt that the oral care was difficult only at the dental office, but not at home. The behaviour and attitude of children toward oral hygiene at home was the distinctive factor between the two groups. Such variations of the effect of ASD-related issues from one child to another could be related to the variation in the type and severity of theses problems.

All the children in the present study was under Autistic Disorder (AD) with only on child was living with Asperger Disorder. Unlike the rest of the participant parents, the parent of the child who live with Asperger Syndrome did no account any exceptional challenges during his oral care. I surmised through his mother account that the ASD-related characteristics were very mild and as the son has no verbal problems. However, factors related to the child himself/herself been reported by most of the parents. These factors included: characteristics related to ASD including: sensory problems and behavioral and communication problems. Other factors like vacillating behaviour and secondary dental pain has been also reported by some participants.

4.1.1.1 Sensory difficulties

According to most of the participant, the sensory problem associated with ASD was a principle challenge to deliver better oral care for their children with ASD. Moreover, children who had sensory problems showed more negative behaviour during oral care process. Unfortunately, none of the other research participants has described the type and the severity of the sensory problem their child suffers. One of the participants expressed explicitly her confusion regarding the sensory problems of her son: "*He is hyper…Hypo! so his mouth is very hypersensitive. That is what the therapist was saying. For me, to just even understand what does that meant? I understand what hypersensitive means, but I couldn't understand the rest of his body was hypo".* She struggled with the sense of the confusion about her son's condition. For many years, she was not able yet to understand from what kind of sensory problems her son suffers. Understanding her son's condition could help her to cope and try to find a solution and avoid consequences from these years of struggling. She continued, "*because then after that began along many years of not only cavities, problems with the actual hygiene. But no solutions on the part of dealing with the hypersensitivity in the mouth. So, I would go publicly and privately. So much money was spent with the occupational therapist. but I got no help necessarily"* This mother struggled to find a viable solution for this issue with oral hygiene and spent the time, effort and money with the occupational therapist but without any actual help. She mentioned many times during our conversation that the sensory problems affect negatively on the oral hygiene for her son. Her son could tolerate neither tooth brushing nor the taste of toothpaste for years: " *This was difficult. This was very difficult. We didn't use toothpaste for a long time. He had a very hard time with the taste. The taste was not appealing to him".* Using words like "difficult" and hard" indicates how intense the struggle with oral care. Suffering with oral care for “a long time” with out actual solution has doubled the suffering and struggle for them with oral care. The simple story of grabbing the toothbrush for most of us was in fact a long story of struggle for her and her son. She found it difficult to break out of the “hard” boundaries of her child’s condition that stood in the way of her ability to help her son. These boundaries left her suffering through an emotional cycle of struggle and worry. Van Manen has written about the proportional relation of caring responsibly and worries: “Caring responsibility increases in proportion to the measure that it is assumed. The more I care for this person, the more I worry, and the more I worry, the stronger my desire to care. Why? Because care is worry” (70).

4.1.1.2 Behavioral and communication concerns.

The effects of ASD characteristics as a barrier to achieve a sense of satisfying parenting were recounted

by another parent who mentioned many times how behavioral and communication problems were a primary factor that complicated oral care for his daughter both at home and at the dental office. This father is a dentist where his identity has greatly affected how he experienced the oral care of his daughter with ASD: *“Well, it is not easy. Because without a verbal communication…and her temper…this was something bothering me from the beginning”.* He explicitly described oral care for his daughter as “not easy”. At the level of language, this description is less intense than some of the expressions used by other participants, but still express the continuous worries that have introduced him into the world of multiple challenges. Being a health care professional, himself, deepened his feelings about these struggles in which he was unable to help his daughter to meet important aspects of her health needs. Providing such healthcare was an integral part of his professional life. His desire to provide the health needs professionally, as a dentist, and emotionally, as a father, has never been achieved as he would do as a dentist or wish as a father.

The second group of parents showed less concern about oral care at home because their children did not refuse to brush their teeth at home. One mother within this group stated that oral care at home was not an issue for her son. Although her son suffered from many sensory issues, he was unexpectedly cooperative during his oral hygiene routine at home: "*He was very good at home…about when he was very young. We always brushed his teeth three times a day. We started like any child…We progressed to the baby toothbrush and we always brushed his teeth"*. There are many possible explanations behind her son's cooperation during tooth brushing. First, his sensory problems may not include the oral cavity. Another possible reason could be that the oral hygiene routine that his parents provided to him from a young age may have desensitized him and prepared him gradually to cope with the stressors that the oral hygiene process might trigger. However, her struggle and worries with the oral care at dental office were considerable: *"But he still can't have his dental work done in a dental chair, like just getting fillings… He has too many sensory issues".* Despite her comfort with her son's oral hygiene at home, the inability to provide full dental care under ordinary dental settings added to her worries and struggle with oral care.

4.1.1.3 Vacillating behaviours

Expressed by two participants, vacillating behavior might be a distinctive feature in the oral care experiences of some children who live with ASD. Vacillating behavior, as described by the parents, is the unpredictability in the child's reaction towards the daily oral hygiene routine. The child could be very resistant some days, and cooperative other days under the same circumstances. This vacillating behaviour was cited by two parents. “*There is also the vacillating of the behaviors. It's like going back and forth, back and forth…one day it's working well, and one day he can be lying… and we can be brush for ever. Another day it is a problem*.” The mother was not able to find an explanation for this unpredictable behavior; hence, they were unable to know what to expect in terms of their child behavior’s day-to-day. The unexpected nature of the child’s behavior could turn tooth brushing into a struggle and add more stress onto the parents.

4.1.1.4 Secondary dental pain and feeling guilty

It is the parent’s task to recognize the pain indicators from their children. However, expressions of pain for children with ASD may be affected by social and communicative impairments. Two participants reported that existing dental pain has negatively affected their children’s response during the oral care process. One mother said that her son did not accept tooth brushing normally, and that although dental pain aggravated his reaction, she was unable to recognize his pain. In this case, the mother noticed the change in her son’s reaction to tooth brushing, but she was not able to understand the cause until they visited the dentist, who readily explained the reason behind her son’s intense negative response to tooth brushing: “*After I brushed his teeth and he was screaming and screaming and I couldn't understand. Now I can understand…When we went to the dentist, he told me that he had an abscess; that's why he's screaming... horrible, horrible”*. Another source of struggle here is the struggle with all the pain associated with the feeling of guilt. The mother could not stop feeling guilty. “For the soul, guilt is the same as pain is for the body. Pain is not pleasant, but warns us that something is out of balance and to look for the cause of this imbalance”. (71)

Another mother stated that her son was normally accepting the brushing and was very cooperative with his dentist when he was younger: *“He would sit in my lap when he was little then he would let the dentist check his teeth and count his teeth [when] he had no cavities.”* The mother, who was routinely able to examine her son’s teeth at home, noticed a cavity in his back tooth. This cavity came after her son started brushing by himself when he was ten years old. She related the shift in her son’s reaction to the development of this cavity: “*He brushed them by himself and it was a very big mistake because then he ended up having a big cavity at the back of his mouth, and he got to the point when you could not have brought him to the dentist.* The son neither expressed pain, nor could she could recognize his pain. Besides the struggle with her child’s oral care, the mother struggled with feelings of guilt. She blamed herself for letting her son brush by himself: “*He wouldn't lie down because he was so nervous to lie down and sit. He was so much stressed. He couldn't do it which is really so bad. Because he got worse and he got another cavity and he got very nervous. He wouldn't let me to brush his teeth.”* Secondary dental pain changed the child’s attitude toward dental care. He refused tooth brushing and got more frustrated at the dental office than usual and started to develop more cavities, until the cavities were finally filled under sedation at the hospital.

4.1.2 Struggling with dentistry

Oral care at dental office was a struggle for all the parents except one. The interpretation of parent’s accounts yielded factors related to the dental team as well as to the nature and the cost of the dental system.

4.1.2.1 But she did not have any experience…

The dental team was a crucial component in the parents’ oral care experience of their children with ASD. The parents recounted two important aspects related to the dental team: lack of knowledge with ASD, and miscommunication. The dental team’s knowledge and familiarity with ASD were strongly related to the participants’ oral care experiences with their children. The parents’ struggle with oral care has been doubled due to the lack of knowledge of dentists about treating children with ASD.

Another of the participant mothers recounted how her son could not tolerate dental visits. The dental visits were challenging for her son and all the major work, including restorative work and extraction were done at the hospital under general anaesthesia (GA). After more than twenty years, this mother remembered very well the experience of her son’s first dental visit. Her son could not cope with the accompanied stress: “W*e made an appointment for him to see that dentist. But she did not have any experience with special needs at all. So, she wasn’t very good at handling him. He couldn’t sit on the chair. He would run around the office. Just waiting at the waiting room...that is just not a very good experience for anyone in that way”.* The mother perceived that the dentist’s lack of knowledge and experience with ASD largely contributed to her son’s reaction. She admitted that her son’s condition affected the outcomes of dental visits, but the first visit was disappointing. As a mother, she had hoped for a typicality for dental visits without struggle. The struggle for her now is to find new ground for hope again. She “can of course still hope, even if the hope is not fulfilled, but then it has the quality of ‘not yet’ fulfilled. (She) still has hope. The disappointment of the hope, however, is the cessation of the hope-act, without a new one having had to take its place”(72).

4.1.2.2 A world apart!

The dental clinic at a children’s hospital was the choice of many participants, partly for financial reasons, and partly to secure a smooth transition if their children would be referred to be treated under General Anesthesia (GA) at some point. However, some of the participants commented on the lack of knowledge about ASD among the resident students at the Children dental clinic. This is one mother recounted her story with her son at the hospital based chrildren’s dental clinic: “*One of the residents there asked me, ‘Are you doing anything? Are you getting any help anywhere else?’ And I'm the one that has to say, ‘occupational therapist, you mean?’ ‘No, it is a world apart from them. It's a world away from them”.* She sensed their lack of knowledge about her son condition. Such incidents made her very disappointed about her choice to take her son to the dental clinic at the hospital for children. She continued: “*The big problem that I dealt with was the Children’s (dental clinic). And the only reason I have stayed all these years is because I knew he would have to see anaesthesia at one point.”* She regretted her choice because she felt that her voice was not heard, and this continued for many years: “*Because you walk-in and you feel like they don't view these hypersensitivities… They don't view it as a problem. That is the only problem… And you are trying to explain to them. You don't think his teeth will be brushed if we didn't have these problems. And all they respond is:" You must brush his teeth. You must brush his teeth. You must brush his teeth”*

Unfortunately, everything this mother said and explained to the dental staff was not actually heard or understood by them. Lack of support and the resulting anxiety were a real struggle for her for many years.

4.1.2.3 If you are a good mother!

Sufficient knowledge and understanding about ASD is important not only for the dentist, but also for the auxiliary dental staff such as the dental hygienist. One participant mother was shocked by a remark from a dental hygienist regarding her son's the oral hygiene at home: "*Probably one of the reasons why I wanted to participate in the study was that I was disturbed by a remark that the nurse had made when I went there. But he hates it. He screams…He can't stand it. It's such an ordeal brushing his teeth. Her response was "if you are a good mother you will brush his teeth".* After many years, this story still disturbs her. Just one comment was enough to make her question her competence as a mother. For that, the mother, and after all these years, still wanted to finish this open dialogue where she left without being able to be a part of that conversation. According to Heidegger, the relationship of care as a phenomenon is "a character-of-being which Being-with cannot have as its own"(73). Her identity of "Being-in-the-world" is defined by her role as a mother and is strongly tied to her mothering responsibilities; otherwise, she would not be herself. She needed to prove, first to herself, her solicitude and care. After the nurse's comment, her reaction and worries intensified, which was a real challenge with which she struggled. She continued: "*Because this wasn't the solution and also when you got a child like that, your reaction becomes three or four times harder …is to work even more than before which is not necessarily beneficial for the child... because my reaction was to brush more… was to impose the toothbrush, making it harder to get it in there".* After receiving a negative massage from a dental expert, the struggle with oral care has been intensified. This judgmental comment about her mothering practices intensified the worry and the suffering for both her and her son. She intuitively knew that her reaction was not the solution, but that she should respond to her child's health needs. This was her responsibility as a mother and a caregiver.

4.1.2.4 Beating you down

"Beating you down" was a metaphor used by one participant mother describing the conversation with dental staff during dental visits at the hospital that treat children. Because of miscommunication, the mother experienced tremendous anxiety and some anger: *"I remember when they told me that he was missing teeth. This was at the last 10 minutes of this appointment and it was a struggle. There was a lot of screaming. [They said] "Oh yes, he's got tons of cavities…By the way, did you know that he is missing teeth? He is missing teeth at the bottom...what kind of syndrome does he have?"*

…. Oh, my God! He is a human… This was too much information that I needed to have in one shot. Slow down. They were very pleased for themselves giving me all this information. I didn't need to know that then…. Throwing all the stuff at me... Beating you down. That making you feel "Oh my God...oh my God." The dental visit was very stressful for the mother and her son. The mother perceived that the conversation with the dental team caused more stress and pain to her and her son. It is the health care professionals' responsibility to help the patient to understand by choosing the right timing and suitable words to transfer their massage. The goal of conversation "is to work toward understanding. It is not assumed to exist simply because we articulated the fact to the person and answered a few questions. Helping someone understand something complex like medicine while the other is distressed by his illness and needs more care than merely offering objective facts"(74). Failing to understand the patient is only "through incapacity to

conversation. Conversation opens up to understanding in ways that can meet the criteria of actually getting to know someone” (74).

4.1.2.5 A big revolving door of people.

According to my participants, meaningful Communication with the dental staff starts when they first meet and greet each other. Some participants felt that it is very important, for the dental staff, to introduce themselves before any dental work begins. One mother recounted how confused she was during the dental visit with her son. She felt more anxious as the dental staff during the dental visits has rarely introduced his self contrary to her experience with the other department at the same Hospital: *“I now take my son's therapist with me to help keep him calm. We make the big day out of the event. and it's a big day in every regard obviously. But when we go there, we don't know who we see. We go in there and it's like a big revolving door of People… I never know what their names are? If they are doctors? This is repeating itself all the time. They rarely introduce themselves. I never know who they are”* For her and her son, the dental visit is a big event, but the miscommunication from the dental staff was under her expectation. A big day for her means more anxiety for her and her son and such simple proper greeting would relief a great part of this anxiety. As a mother of son who live with chronic condition like ASD, She would expect a greater sense of connectedness with health care provider.(75) Establishing a positive dialogue between the doctor and his patient is the first step to ease the fear and introduce the hope for positive future.(76) According to Jim Olthuis, “Squarely in the heart of suffering, compassion has the ability to deliver from loneliness, offering the touch of love and the power of courage to persist and endure”.(77) For this mother, healthcare staff failing to introduce themselves is failing to show compassion and respect from the beginning. Failing to establish this important relational connection has threaten the hope of an empathic connection with the health care provider that could help her to move the first step in her son's healing Journey.(76). The careful compassionate responses from the doctors to their "patient's emotional wellbeing as they manage the chronic illness fosters an emotional atonements from which enhanced healing may emerge" Hovey wrote.(76)

On the other hand, this mother recounted how comfortable she felt when she visited her son Orthodontist for the first time not only because of expertise to manage her son, but also because he successfully connected with her through positive conversation: "*When I came home, I looked it up on the internet because I thought this is a little bit bizarre to speak to somebody who seems to know a lot more than the average in terms of questions. We were very surprised that he had his fingers in [my son's] mouth for 20 minutes. [My son] was calm and the doctor was talking to me while he has his fingers in his mouth. He knew what he was doing. He was someone else. And his first question to me, the doctor, was: are you still brushing his teeth?".* I remember how happy she was when she narrated this part. Her voice, tone and her gaze all looked different. Both, the Orthodontist' s knowledge with dental management of children with ASD and his capacity to converse with her had a great impact on her perception toward the dental visit. The orthodontist's first question was latent with understanding and compassion: *" This is why I was happy with the Orthodontist. I am happy because he was speaking with me. He was having a conversation with me. He was exchanging things. He was answering my questions. I'm a part of something here".*

4.1.2.6 I need to talk about money

The cost of dental services was also cited by many participants as a major factor in their experiences with oral care for their children living with ASD. These participants perceived the cost of dental services as very expensive, which may have magnified the stress that they already experienced in terms of their child's overall oral care. All the participant who struggled with the cost living in Quebec where children with ASD who did not receive dental insurance or support. Although all the basic dental procedures are covered, as for all children, under provisional health insurance, there are still some dental procedures that are not covered, such as dental sealants. Sealants are dental materials that are applied on the occlusal surface of permanent teeth to prevent the cavities AND highly recommended as a preventive measure for all children with who live with ASD (78). highly recommended as a preventive measure for all children with who live with ASD (79). One parent explicitly commented on the cost of dental sealant. The dentist at the hospital recommended the sealant for her son, and they applied it to his teeth under general anaesthetic while he was undergoing other needed dental procedures. The mother recounted: *"…she suggested to put a sealing on the teeth. So if you don't brush teeth well, sealing will protect the teeth almost for life, she said. She recommended it. It was very, very expensive."*. The cost was not always directly limited to the cost of the dental procedure. When the child has sensory issues that interfere with proper oral hygiene, the child usually needs rehabilitation through occupational and/or psychological therapy. This indirect cost was cited by one mother who confirmed that the psychological therapy was very helpful to desensitize her son toward tooth brushing. After her son, had developed many cavities and been treated under general anaesthetic, she strongly felt that dentistry had failed to provide a practical solution to her son` sensitivity to dental brushing. She inquired with his psychologist in the private sector to seek a solution: *"then with the psychologist with the private psychology…I need to talk about money… private psychology: $150 a week to have somebody come and help you privately deal with this, but this helped".* The psychologist, who provided his service at the mother's home, was very helpful, finally the son started to brush his teeth by himself with no or little help from his parents.

4.1.3 Struggle related to lack of partner support

"You may feel lonely among a lot of people, but you may feel happy with one person. It's not related to the number of those around you, but related to the heart on your side"

Kahlil Gibran

Social support has a crucial effect on the outcomes of oral care experiences for children with ASD. A supportive environment can greatly facilitate parents' oral care tasks for their children. Partners, support groups, or centers are all important; however, I have noticed through the participant accounts that the participation of their partner was very important. The participation of the other partner means that there is another person who can emotionally, physically, and financially help to meet the child's special needs on a daily basis. Most of the participants explicitly reported the importance of this support. This father, for example, praised his wife's supportive role with their daughter and the whole family:*" It may be more challenging for the mother who is facing that more than me. She sacrificed even her job and most of her social life. Just to be around to do something. For me, maybe, I have a space to breathe… to communicate with people. But what makes this family is going on is the mother. She is the one who. and it is not easy".*

On the other hand, the absence of the other partner, or a partner who is deficient in his/her role creates a heavy load for one parent and a feeling of inability to satisfy the child's health care needs. One participant expressed how difficult it was for her, as a single mother, to meet her son's health care needs. She felt that the absence of the father was the primary factor that made the oral care process so difficult: "*It is very difficult for his teeth. Because I'm a single mom right now. I am divorced. it was very hard doing that by myself".* The sense of loneliness was evident in her words. The feeling of loneliness intensified the burden of her son's oral health care needs and left her suffering from a feeling of inadequacy in needing to bear all the responsibility. According to Emily White "With loneliness, that sense of a presence begins to vanish over time. What lonely people find themselves drowning in is absence. They have to struggle with the unnerving sense of being too much on their own, and having to rely on themselves in an effort to meet their own needs. And once the self has been searched and patted down for a sense of companionship – which is something it can't provide – what the lonely person is left with is a worn-out, edgy sense of insufficiency." (80). Not having a supportive partner around meant that she had no access to the emotional, physical, and financial support that would give her the energy to continue.

4.2 Finding #2: Oral care as a hope

"Hope" is the thing with feathers"

Emily Dickinson's

Overall, the participants felt that their experiences with their child's oral care improved over time. Each participant had a story behind this improvement. Participants felt that their children had become more accommodating with the tooth brushing process, and this provided hope for the future. Despite all the challenges, the parents continued to provide the oral care at home as much as they could. Struggling with oral care place the parents in-between struggle and hope, with disappointments and at times feelings of hopelessness describes this struggle. The struggle and solitude so to speak was tempered by love for their children which has nourished their (hope).

4.2.1 Struggling with (out) giving up

A disposition towards "giving up" has been a feature of the oral care experiences of many participants. All of the aforementioned struggles with oral care were responsible for creating the sense of giving up on oral health care, both at home and at the dental clinic. Through these narratives from participant parents, I identified two main elements that affected parents' will to continue with the struggle: hopelessness and disappointment (72).

One participant explained how the long-term struggle with oral care for her son introduced her to the world of suffering with "hope rivals": The hopelessness and the disappointment: *"Because you're not doing it over it you're doing it over many many years...It's not going to take a year and will have this problem solved. We're doing this now so we've been working on this for 10 years or 12 years".* The "restrictive repetitive way of being in the world" (81) was very stressful and led her to feelings of hopelessness and a desire to give up: “ *That is when you begin to feel as a parent you just almost feel like you're just going to let it go... I am not gonna try anymore. I am not gonna keep trying this”.* The unsuccessful efforts over (*many many*) years led her to a state of hopelessness. The more she wanted to experience trouble-free oral hygiene with her child, the deeper the hopelessness she suffered. “we only become ‘hopeless’ with regard to something toward which we are striving, with respect to something we want to or try to achieve or want to happen” (72). As such, dentistry was responsible for the other elements of hope rivals: The disappointment. The mother continued to describe the feeling of disappointment: “After *ten years of this, [I am] like I can't I can't. But if something in place to help earlier, you wouldn't be at 12 years dealing with[that]”.* Struggling with oral care for over ten years without receiving any real support was very disappointing for her. Disappointment, being dependent on hope, only appears if hope was there in the first place; “the experience of a disappointed hope must follow upon the actual experience of hope. For a hope to be disappointed, then, a specific hope-act has to be carried out, which is then not fulfilled or otherwise negated” (72). Because trials involve a sense of uncertainty, they ultimately chose to give up, as a kind if temporary surrender to rest and recover. However, disappointment and hopelessness in the moment do not mean a total loss of hope. “Hopelessness is not a cancellation of the specific hope”(72). The tension between hope and giving up is ongoing and helps us to understand the experiences of these parents with their children.

4.2.2 It is improving

One parent expressed how his daughter got more cooperative, over time, because they "never gave up" and continued to list the oral hygiene in her daily routine: “*she gets it as a routine, but she always feels [like] we are hurting her? Because she never understands that it is important for her. But now she keeps be unhappy!’. but she accepts that we need to do that*”. The parent felt that his child became more cooperative during tooth brushing over time. Even though she still expressed some discomfort, her reaction toward the oral hygiene is, generally, improved. Since children with autism naturally tend to be receptive to routine (82). Integrating the tooth brushing into her routine might be the cause of this improvement. It is also possible that the sensory dysfunction typical of autism may have decreased as the child got older. (83)

4.2.3 I said no more...

Most participants reported that their children had been treated for dental procedures under sedation in a hospital setting. The interviews revealed that parents were more worried about their child’s oral health after such a procedure. All participants felt that General Anesthesia (GA) is the best choice to treat their children dental needs when "unavoidable". However, one mother expressed how their son’s surgery changed her resolve around dental care. “*But after the last surgery, I said no more. No more surgeries. No more cavities. We’re going to do it and it was difficult. We had two years where my husband was like: okay I'm going to leave the room now it's just like I can't do this anymore. It psychologically weighs down”.* After their children underwent dental procedures under GA, parents were more motivated to act to improve the oral hygiene of their child. The surgical procedure intensified their resolve. The pain associated with struggle charged them with hope for improvement. Hope is an essential characteristic of human beings. By sharing their stories, the participant parents presented the idea of not giving up or resolve which means the experience of hope. The parents worked hard in the hope that they could create better oral care experiences for their children in the future. The participants translated this resolve into practical steps. For example, some parents insisted on checking the child's oral hygiene themselves. This mother described he intensity of her reaction after the sedation: "*Now I am saying to him there is no way. You don't have other cavities. I don't care how old you are. He brushes his teeth by himself which is fine. Even if they are clean, I check them once a day to make sure they are perfectly clean".* The more she worries and fears, the more her hope grows. According to Heidegger: "Fear is the fearing in the face of something threatening of something which is detrimental to Dasein's factical potentiality-for-Being" (73). The fear is the response to the threat of her son having dental cavities and being exposed to another surgery. Heidegger suggests: "Hope has sometimes been characterized as the expectation of *bonum futurum,* to distinguish it from fear, which relates itself to *malum futurum*. But what is decisive for the structure of hope as a phenomenon, is not so much the 'futural' character of that *to which* it is relates itself but rather the existential meaning of *hoping itself*". Hope and fear as phenomena are related to each other in important ways. It is possible for the hope and fear to antagonize or harmonize (84), and in the case above, the relationship between hope and fear was harmonious. The more the mother feared, the more she hoped and reacted.

Another mother described the improvement in her son's attitude toward oral hygiene as being late and slow. When asked how this improvement came about, she recounted that during the follow up visits after her son's dental surgery at the Children's Hospital, the dental surgeon gave her simple tips, which were very helpful in easing the struggle with oral hygiene. While she was grateful for the advice and found the tips very helpful, the mother also expressed feeling disappointed that this helpful professional advice was not offered to her sooner: *"We had the head of the department I guess she is now retired. She (is the one who) did the surgery. So, she came and followed up. (She) looked at his teeth when he went back to double-check after the surgery. And one of the things she said to me, not only helped, but this was after many years and after all these cavities".* She perceived the dentist as the professional primarily responsible for offering her advice regarding her son's oral hygiene. She felt that her son's struggles with oral hygiene were preventable if there had been earlier help. Though there were no special organized programs to help her with her son's oral hygiene problems, the hope of improvement made her keep going to the dental clinic. Her worries and cares about her son continuously supplied her with hope.

The mother never gave up and continued looking for a solution to her son' problems with oral hygiene. She resorted at last to psychological treatment. Together with a private psychologist, she set up a behavioural plan to encourage the son to accept the oral hygiene process gradually: "*It will change then with the psychologist. With private psychology…We started with put in a charge. Every five tooth brushes, you get a prize. Then every ten you get a prize and every 15 you get a prize and every 20 you get a prize. Then after 30. Then he worked out perfectly. When we arrived every 50, I stopped. No more prizes. It was over in about three months".* The hope of improvement provided her with the energy to continue, despite her previous disappointments with the dentistry field. Simple behavioural management, using positive reinforcement, worked effectively with her son: "Now *he brushes his teeth. If he is in a bad mood, we will say: there's the* *prize…but that's not every night and that is not every morning. That's not all the time".* Anthony Steinbock stated that "The hope-act is fulfilled when the hoped-for event arrives in the manner in which the hope-act was directed"(72). Though her son would vacillate sometimes and refuse brushing, the improvement in general, has fulfilled her hope. For a mother who was struggling every day with oral hygiene of her son, such improvement is very satisfying.

5 CHAPTER V: DISCUSSION

This study provides a phenomenological evaluation of the oral and dental care experiences of parents of children with ASD. More specifically, the study identifies both real and perceived barriers to oral and dental care, which parents must face. To the researcher's knowledge, this is the first qualitative study to explore the oral and dental care experience of children who live with ASD in Canada. Very few qualitative studies have been done on this topic and the literature review revealed only one other published study that explored the oral and dental care experiences for children with ASD from the parents' perspective.

The interviews revealed that the experience of parents with the oral care of their ASD children was one of struggle, wanting to give up and hope. The experience of struggle was mainly related to factors related to the child itself, including ASD-related factors that made oral hygiene activities, like brushing, difficult. In this study, the main ASD-related characteristics were sensory problems communication problems and vacillating (swinging) behaviour. Sensory and communication problems were strongly related to the uncooperative behaviour of the ASD child during the oral care process in this group. This was consistent with other studies that showed that child negative behaviour was the main barrier to better oral care among ASD children (23, 25, 26, 30, 85). Parents of children with ASD also report that sensory sensitivities have a negative impact on the oral care experiences of their children (29, 31, 86, 87). These experiences take a toll on the parent's well-being. A study done in the UK examined psychological distress in a group of mothers raising children with ASD and found that mothers whose their children displayed more challenging behaviours experienced higher levels of stress. (88)

The findings also showed that parents struggled with the vacillating behaviour of their children during oral hygiene process. The children would accept the tooth brushing for a period of time and then suddenly refuse it without any obvious reason. Parents mentioned trying to use rewards as positive reinforcement to accommodate such instances. However, the usual rewards did not work as the children grew and parents struggled to find new rewards to encourage their children to practice the oral hygiene as before. Considering that vacillating behaviour was cited by only two participant parents, more investigation is needed to understand this behaviour.

Other factors related to dentistry also emerged as being influential. Two participants reported struggling with oral care because of secondary dental pain, which triggered avoidance behaviour during the oral care process. This finding was consistent with another study that showed that a child could exhibit negative behavior during a dental visit as a reaction to existing dental pain.(3) Non-verbal children cannot express their pain; previous work has shown that parents cannot accurately describe the level of pain in their children with Autistic Disorder (AD).(89) Being unable to understand that their child was in pain left two parents struggling both with the uncooperative behaviour and feelings of guilt. This has an important implication during the dental visit in terms of predicting the child behaviour during the dental visit by understanding the potential factors associated with uncooperative behaviour of the child.

Parents also struggled with dental services. A lack of knowledge of ASD in the dental team (dentists and hygienists) and frequent miscommunications were described by parents. Other studies have suggested that the perceived lack of knowledge of ASD among dental teams discourages parents from bringing their ASD child in to visit the dentist (3) and that parents sometimes face difficulties finding a dentist who is willing to treat their child. (29) On their side, dentists have reported that being unprepared to treat children with disabilities due to a lack of knowledge and training was the main reason behind their unwillingness to treat them (30). A qualitative study from the USA investigated the efficiency of incorporating a special course on special needs patient for the dental hygienists.(90) These courses improved students' awareness, critical thinking, problem solving and professionalism; hence preparing dental hygiene students to provide the services to special need patients. Preparation of the student by incorporating a service learning course is an important investment to improve the quality and accessibility of dental care for children with ASD. (30)

The lack of knowledge of ASD among dental staff seems to be related to the frequency of miscommunications parents reported in this study. A previous study that explored the health care experiences of preschool children with ASD from their mothers' perspective (91) found that health care practitioners often did not understand the broad dimensions of ASD as a condition and how it affects the overall health of children and their families. (91) The study suggested that the mother's voice and concerns did not receive enough consideration by the medical staff. (91) In support of the current findings, concerns related to a lack of proper greeting have been raised by mothers of children without autism, who deemed they were improperly greeted by paediatricians and requested to be called by their first names instead of "Mum". (92) Of course, to introduce themselves properly is an important part in the greeting process that dentists and hygienists could use to ease stress and enhance the parent's perception of receiving better oral health care for their children. (74)

Parents also report struggling with the cost of dental services. This is consistent with many studies that reported that the cost of dental care can be a barrier to access among children with ASD. (3,

23) In the USA, more than a third of the parents in one study reported difficulty affording the cost of dental treatment (23). In Toronto, Gadi et al. (2011) stated that about a quarter of the participant parents find it difficult to meet the cost of dental services. In Quebec, where the current study was performed, governmental dental insurance for children with ASD provides the same coverage as for children without ASD, (3) including basic services without the GA and other recommended dental treatments that children with disabilities might require. The findings also point to several indirect costs of dental care, such as the cost of hiring a psychologist or occupational therapist to help the child accept dental hygiene. Lewis and Vigo, Novak and Klein (2016) have also found that parents of children with ASD use their children's school program to train their children on the oral hygiene (85). The findings of the current study suggest that more effort should be made to improve collaboration among different professional supports for children with ASD, such as occupational therapists, psychologists and dental health professionals, to ensure the delivery of more efficient services.

Partner support has been also an important feature in this study's findings. In this sample, there was only one participant who explicitly related a great deal of her struggle with her son oral care to her status as a single mother. Similarly, a study in UK stated that single mothers of children with ASD are more likely to report lack of support and more psychological distress. (88)

These struggles led to the parents contending with feelings like wanting to give up. However, this experience was transient. Giving up was a "state-of-mind" and although transient, this attitude might have affected the oral health status of children with ASD. In fact, a systematic review has found that the prevalence of caries and periodontal disease are higher among children living with ASD. However, parallel to the "the struggle with giving up" there was always a feeling of "hope".

Major events in the oral care process like having dental work done under GA was a strong motivation to create a hope of improvement and to work harder to achieve better oral care for the child who live with ASD. Such simultaneous, contradictory feelings as discouragement and hope have been reported others who explored the families' experiences of raising a child with a disability. (93) (94) Lason et al. (1998) found that both despair and hope could be enfolded in parents' accounts at the same time. (93) Such discrepancies in feelings are explained by parents through the interaction "between experiencing the impossibly difficult demands of parenting a child with autism and loving that child no matter what." (94) In contrast to the former two studies which were reflections of a parenting experience where the parenting practices have been extensively explored, the current study used the lived experiences of parents instead of the parenting experience in an attempt to capture a parenting experience together with other relevant oral care experiences of the child with ASD. These findings also suggests that parents could experience "giving up" during the oral care of their children with ASD but not "despair" as has been suggested by the other parenting experience of children with autism.(94) Two components that led to the feeling of wanted to "give up": the struggle with child oral care and the disappointment from unresponsive dental services. More research is needed to understand the tension between giving up and hope and its effect on the oral care experiences of parents of children with ASD.

In conclusion, this study is the first phenomenological study to capture the oral care experiences of parents of children with ASD. Because of the limited qualitative literature that explored the oral care experience of children with ASD, findings related to my study provides a unique understanding of the oral care experiences of those children. I believe that more studies are needed to further understand different aspects in the oral care experiences of children with ASD.

6 CHAPTERVI: SUMMARY & CONCLUDING COMMENTS:

To my knowledge, this is the first phenomenological study to address the oral care experiences of children living with ASD. In fact, a very limited number of studies have addressed this question; therefore, this study enriches the literature on oral care issues in children living with ASD in Canada by providing a critical current understanding of their parents' experiences. This study is of particular value to new parents of children who live with ASD, as it provides the basis for them to learn how to tend to the oral care needs of their children efficiently and with less stress. It is also of value to dental professionals and policymakers who interface with this population, as the real stories that parents shared provide an overview of the current oral care context of children living with ASD in Canada. This information will allow them to craft new policy proposals to fill potential gaps and provide better oral care to children living with ASD.

6.1 The methodology:

This study used the traditions and an application of the IP approach through semi-structured interviews to delve deep into the experiences of parents of children with ASD. I followed Heidegger's recommendations to analyse the data and provide an insightful and reflective understanding of the parents' experiences. I was also influenced by Van Manene's work and philosophy during my analysis, interpretation and reflection on the participants' experience.

6.2 The participants

All participants in this project were highly educated. Out of the six participants, five were mothers and one was a father. The interviews brought out a rich experience in terms of oral care. All children, but one, were diagnosed with Autistic Disorder (AS) rather than other conditions included under the umbrella of ASD. One child was diagnosed with Asperger Syndrome, and the experience of this parent is different from that of the other participant parents. Parents who have children with AS in this study display many similarities in terms of their oral care experience. It is highly recommended to explore the oral car experience of all the conditions that fall under the ASD umbrella separately in future work.

All six interviews were conducted between December 2015 and December 2016. Since the invitations were sent to private centers that deal with children with ASD younger than 10 years old, the response was very low. The recruitment process could have been enhanced by attending centers and/or hospitals that provide dental services for adults with ASD.

6.3 Oral care experiences of children with ASD, parent's perspective

The following themes emerged from the analysis of the data. Two main themes defined their experiences: "Oral care as a struggle" and "Oral care as a hope". The tone of struggle was intense and led to the experience of feeling like giving up. However, their care for, worries about, and love toward their child charged them with hope for betterment. The hope for better oral care antagonized the feeling of giving up.

6.4 Oral care as a struggle

The parents reported an experience related to the oral care of their children living with ASD which danced between struggle and hope. The parents' struggle with the oral care of their children stems from several sources, including: the child him or herself, issues with dental services, and/or a lack of partner support. ASD-related characteristics, such as sensory, behavioural, and communication problems, were the main source of struggle for most parents and their children.

For some parents, oral care both at home and at the dental clinic was problematic and challenging for their children. For others, the struggle was primarily at the dental office. I believe that these variations were mainly related to differences in the type and severity of the child-related problems. Another possible explanation for these variations was that some parents could have been able to provide a sensory adapted environment during oral hygiene routine at home, while this was not possible at the dental office. Indeed, a gradual approach has proved to be very beneficial to enhance the adaptation and cooperation of children living with ASD during the oral care process.

Some parents struggled with feelings of guilt when they realised they did not understand the dental pain their children suffered. Also, parents reported that secondary dental pain was the main reason for a negative change in their child’s attitude during the oral care process both at home and at the dental clinic.

Vacillating behaviour during the oral care process was a source of struggle for some parents. Parents defined vacillation behaviour in that though the child could accept the oral hygiene without any struggle some days, on other days, he or she could refuse it for no obvious reason. The anticipation of a negative reaction from the child toward oral care was a great source of struggle for some parents.

Dental professionals could also be a crucial source of struggle. Some parents reported that there was a lack of knowledge regarding ASD among dental staff. Some parents were very disappointed by the dental professionals’ lack of awareness of their child’s issues. For example, parents reported that dental staff would ask very basic questions regarding their child’s condition or totally fail to deal with the child effectively during the dental visits. This lack of knowledge led to miscommunications which frustrated parents. Some parents reported that dental staff made judgmental statements such as “if you were a good mother, you would brush his teeth”. Parents also reported that dental staff failed to choose the right timing and wording when communicating with them, or failed to properly introduce themselves during the dental visits. In terms of access to service, the cost of dental services was also reported to be a source of struggle, particularly for parents who live in Quebec where dental insurance for children who live with ASD covers only basic services, without including dental sealant, which most parents reported needing for their children.

My findings also demonstrate the importance of having a supportive partner to help achieve better oral care for children with ASD. One parent explained how being a single mother intensified her struggle with her son’s oral care. Not having a supportive partner meant feeling lonely and lacking the emotional, physical and financial support needed to achieve optimum oral care.

All the above-mentioned challenges can work as barriers to better oral care. The course of raising a child living with ASD can be challenging, and oral care is only one part of the special care process. Every effort should be made to ensure oral care is more accessible and easier for parents and their children. Simple improvements, starting with preventive measures and oral hygiene at home could be better supported by teaching parents how to deal with the sensory and behavioural issues at an early age. This could be achieved more effectively in collaboration with other departments like psychology and occupational therapy. This kind of early intervention is important to avert the pain and struggle with oral care these families suffer.

Furthermore, dental students and hygienists should learn more about oral care for children living with ASD. This could be accomplished by incorporating a special course in the dental care program about dealing with children with disabilities in general, and ASD specifically. Also, more research is needed to understand sensory issues for children with ASD in order to provide a sensory adapted environment at the dental clinics for children living with ASD. Policymakers should seriously consider extending the dental insurance offered to children living with ASD. Special attention should be paid to the single parents raising children with ASD to support them in the oral care process.

6.5 Oral care as a hope

The continuous struggle with oral care for children living with ASD creates a feeling of wanting to give up among several parents. They suffer through a state of disappointment and hopelessness; especially if they struggled for an extended period without receiving help. However, disappointment and hopelessness in the moment does not mean a total loss of hope. In the end, parents always found their way back towards hope.

It is essential to intervene in the path of struggle and stress via the development of a specially designed oral care program for children living with ASD and their families. Workshops should be provided to teach families how to properly perform the oral hygiene steps, and programs should be developed to encourage successful dental management for children living with ASD.

Most participants expressed that, over time, their children became more compliant during the oral care process, particularly at home. However, this was not before all children underwent GA procedures for their dental work. Incidents like the child undergoing GA for major dental work were a great motivator to parents to hope for improvement. The parents' care and solicitude were translated into actual steps to provide better oral care for their child. Collaborations with other professionals such as psychologists were unexpectedly helpful parents and allowed them to improve their children's reaction toward oral hygiene. More research is needed to study the facts behind the perceived improvement of the children's attitudes toward oral care.

In the end, the struggle with oral care is avoidable. Although it is necessary to set priorities in managing ASD-related disabilities, such as language learning difficulties, proper oral care should not be overlooked or postponed. More care should be offered to help parents maintain proper oral hygiene at home by understanding each child's individual oral care approach and needs. This must be followed by early professional preventive measures, including providing adequate training to dental students to prepare them to better serve this population. Preparing students would make them more confident and more successful at providing dental services to children living with ASD. Therefore, more studies are recommended to understand and apply the best clinical approaches during the dental visits.

7 APPENDICES

7.1 APPENDICES(A) INTERVIEW GUIDE SAMPLE

INTERVIEW GUIDE

- **General questions:**

I. When was your child diagnosed with ASD? What did it mean to you?

II. How would you describe your child general health?

- General questions related to the research question:

  - Questions related to oral health of their child

I. How would you describe your child's oral health experience?

II. Can you tell me about his eating habits? Do you think it affects his oral health condition?

III. Could you describe a daily routine for your child's oral care?

IV. Do your child/ daughter face any difficulties to maintain oral hygiene at home? If so, how did you address it?

V. What about the dental visits?

VI. Does he or she receive governmental support to cover dental visits?

- Questions related to oral health of their recommendation
  I. Can you talk about what have you learned that would be helpful for new parents to know about oral health care for their child?
  II. What would you like dental students to know about when treating children with ASD?
  III. Are you satisfied with your child's oral health care experiences? Why or why not?
  IV. Could you mention three things you wish to change in the current dental health system. (in order to fit the children with ASD)?

➢ Other questions

I. Is there anything else you want to tell me about?

II. Do you have any question to the other parents who have children with ASD?

III. Can I call you in future in case I needed some clarification?

7.2 APPENDICES(B) CONSENT FORM

McGill

Faculty of Dentistry

McGill University

3550 University Street, Rm.205

Montreal, QC, CANADA H3A 2A7

Richard Hovey, PhD

Tel: 514-398-7203, ext. 09056

Fax: 514 398-7220

E-mail: richard.hovey@mcgill.ca

Faculté de médecine dentaire

Université McGill

3550 University Street, Suite 205

Montréal, QC, CANADA H3A 2A7

Research Participant Consent Form

Oral Care of Children with Autism Spectrum Disorder

Oral health experiences, understanding the challenges and barriers for children living with Autism Spectrum Disorder: a parent's perspective.

Research Project Leaders:

Dr. Richard Hovey, PhD

Email: richard.hovey@mcgill.ca

Division of Oral Health and Society, AWCRP

McGill University

3550 University Street, Suite 205

Montreal, QC H3A 2A7

Tel: 514-398-7203, ext. 09056

Fax: 514-398-7220

Dr. Amina Abomriga, DMD

Graduate Student (MSc)

Division of Oral Health and Society,

Faculty of Dentistry, McGill University

2001 McGill College, Suite 500 Email: amina.abomriga@mail.mcgill.ca
Montreal, QC H3A 1G1

Introduction:

You are invited to participate in a study that explores the experience of children with Autism Spectrum Disorder (ASD) with respect to their oral health care, from a parental perspective.

The purpose of this study is to gain insight and understanding through the experiences of parents of children with ASD and learn first-hand how their children attend to oral health practices at home as well as how oral health professionals understand and treat children with ASD.7u67

In order to accomplish this, we plan to conduct parental interviews with 5 to 10 participants who have a child diagnosed with ASD who is at least 10 years of age. The interview may last approximately 30 to 60 minutes. Participation is completely voluntary and participants may stop the interview at any time during the interview process without prejudice. The interview will relate to the child's oral care experience at home and dental office.

Risk and Discomfort:

There is no known risk involved in participating to this study. The participant can stop or suspend the interview at any time without prejudice.

Potential Benefits:

There is no direct benefit to participants; however, they will provide researchers valuable information in understanding unexplored aspects of oral health care for children with ASD.

Confidentiality:

Upon your consent, the interview will be audio-recorded. All recordings will be destroyed once transcribed. All personal information obtained through this project will be kept strictly confidential. For the purpose of protecting the participants' identities, their names will be deleted from the transcripts. Access to collected data will be restricted to the research team and data stored securely in their password-protected personal computers and/or desktop at McGill University/MUHC. The results of this research (including direct quotes) may be published and presented at research meetings and conferences. The participants' names and their identity information will not be mentioned. Transcriptions of the interviews will be destroyed approximately 36 months after analysis.

Voluntary Participation and / or Withdrawal:

Your participation in this study is completely voluntary. You may withdraw your participation at any time without explanation and without penalty. Should you decided for any reason to terminate your participation before, during or after the interview, all the data will be deleted from the audio recording and if it had been transcribed all copies will be shredded immediately.

Questions and Contact Information:

This research has been reviewed and approved by the Institutional Review Board (IRB) of McGill University. The IRB may access the data to monitor ethics compliance/sound management of the study.

If you have any question about your participation, please contact Ilde Lepore, IRB Senior Ethics Administrator at 514-398-8302. If you have a question about this research project, you may contact Dr. Richard Hovey or Dr. Amina Abomriga.

Sincerely,

Richard Hovey, PhD

ORAL CARE OF CHILDREN WITH AUTISM SPECTRUM DISORDER

Oral health experiences, understanding the challenges and barriers for children living with Autism Spectrum Disorder: a parent's perspective.

Declaration of Consent:

The study has been explained to me. I have read this consent form and understand the following information:

- My participation in this project is voluntary; I have the choice to withdraw my consent and to discontinue my participation in this project at any time without explanation.

- My decision regarding whether or not to participate will have no effect on my status. Refusal to participate will bear no penalty or loss of benefits.

- A single interview will be conducted by one of the two lead researchers and will be digitally audio-recorded and transcribed.

- The confidentiality of all verbal and/or written information I provide will be respected; all identifying information will be removed from the written interview transcripts and will not appear in any published documents.

- The results of this study may be used anonymously in research publications and meetings.

- I have had the opportunity to ask questions and all of my questions have been answered to my satisfaction.

STATEMENT OF INFORMED CONSENT

By signing this consent form, I do not waive my legal rights. I agree to participate in this study as described above.

Participant's Signature: ……………………………………………………………………………………………….

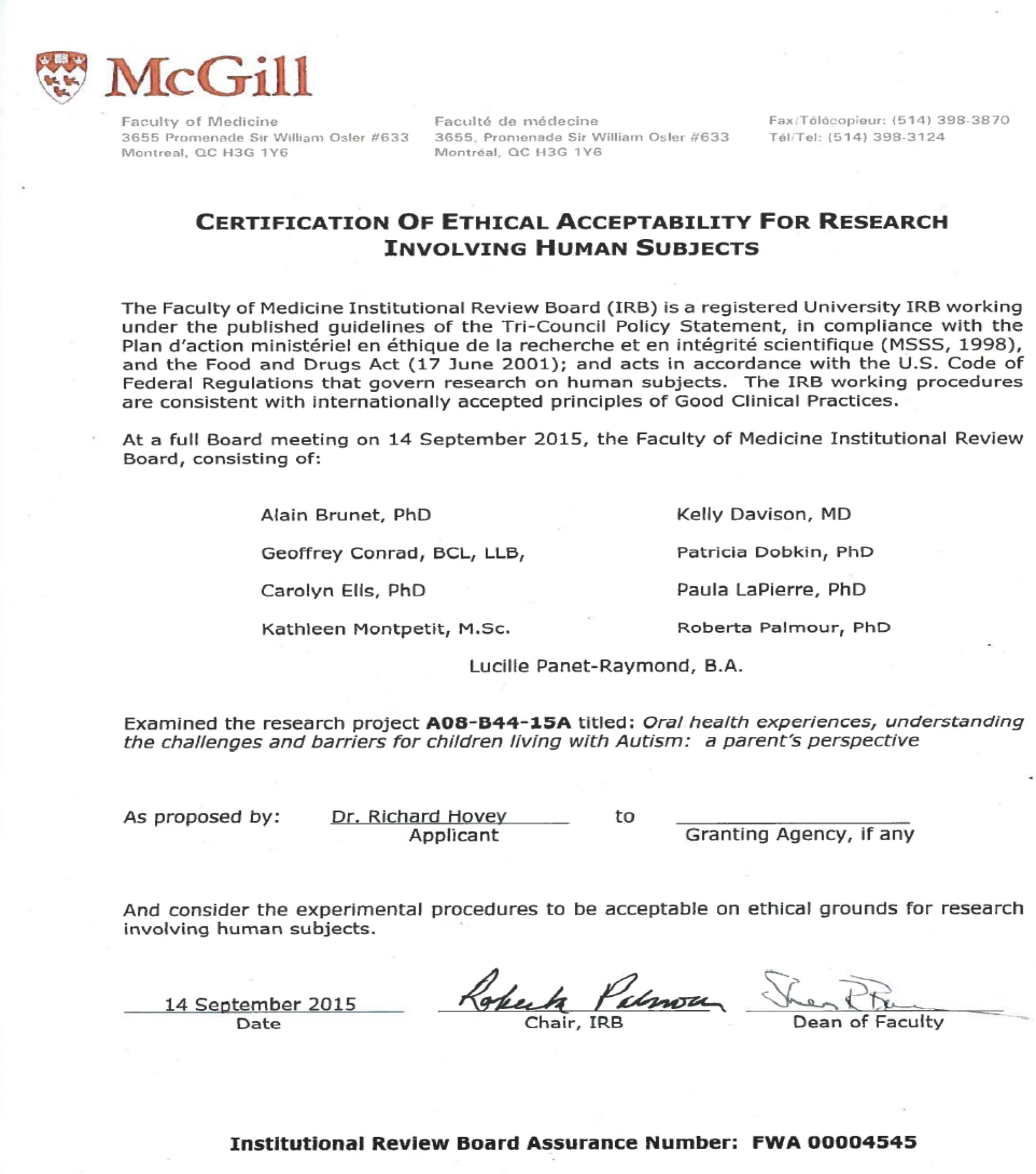
Print Name: ……………………………………………………………………………………………………

Witness: ……………………………………………………………………………………………………….

Print Name: ……………………………………………………………………………………………………….

Date: …………………………………….. Lead Researcher: …………………………….

7.3 APPENDICES(C) ETHICS APPROVAL



McGill

Faculty of Medicine
3655 Promenade Sir William Osler #633
Montreal, QC H3G 1Y6

Faculté de médecine
3655, Promenade Sir William Osler #633
Montréal, QC H3G 1Y6

Fax/Télécopieur: (514) 398-3870
Tél/Tel: (514) 398-3124

CERTIFICATION OF ETHICAL ACCEPTABILITY FOR RESEARCH INVOLVING HUMAN SUBJECTS

The Faculty of Medicine Institutional Review Board (IRB) is a registered University IRB working under the published guidelines of the Tri-Council Policy Statement, in compliance with the Plan d'action ministériel en éthique de la recherche et en intégrité scientifique (MSSS, 1998), and the Food and Drugs Act (17 June 2001); and acts in accordance with the U.S. Code of Federal Regulations that govern research on human subjects. The IRB working procedures are consistent with internationally accepted principles of Good Clinical Practices.

At a full Board meeting on 14 September 2015, the Faculty of Medicine Institutional Review Board, consisting of:

Alain Brunet, PhD
Geoffrey Conrad, BCL, LLB,
Carolyn Ells, PhD
Kathleen Montpetit, M.Sc.
Kelly Davison, MD
Patricia Dobkin, PhD
Paula LaPierre, PhD
Roberta Palmour, PhD
Lucille Panet-Raymond, B.A.

Examined the research project **A08-B44-15A** titled: *Oral health experiences, understanding the challenges and barriers for children living with Autism: a parent's perspective*

As proposed by: Dr. Richard Hovey (Applicant) to ____________ (Granting Agency, if any)

And consider the experimental procedures to be acceptable on ethical grounds for research involving human subjects.

14 September 2015
Date

Chair, IRB

Dean of Faculty

Institutional Review Board Assurance Number: FWA 00004545

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