

Photocopy and Use Authorization

In presenting this thesis in partial fulfillment of the requirements for an advanced degree at Idaho State University, I agree that the Library shall make it freely available for inspection. I further state that permission for extensive copying of my thesis for scholarly purposes may be granted by the Dean of the Graduate School, Dean of my academic division, or by the University Librarian. It is understood that any copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Signature _____

Date _____

UNDERSTANDING ORAL CARE EXPERIENCES OF
YOUNG ADULTS WITH
AUTISM SPECTRUM DISORDER

by

Lauren B. Mirsky, RDH, BS

A thesis

submitted in partial fulfillment

of the requirements for the degree of

Master of Science in Department of Dental Hygiene

Idaho State University

Summer 2020

Committee Approval

To the Graduate Faculty:

The members of the committee appointed to examine the thesis of Lauren B. Mirsky find it satisfactory and recommend that it be accepted.

Ellen J. Rogo, RDH, PhD
Major Advisor

JoAnn Gurenlian, RDH, MS, PhD
Committee Member

Steven Moody, PhD
Graduate Faculty Representative

Human Subjects Committee Approval

January 6, 2020

Lauren Mirsky
Dental Hygiene
MS 8048

RE: Study Number IRB-FY2020-117: UNDERSTANDING ORAL CARE
EXPERIENCES OF YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER

Dear Ms. Mirsky:

Thank you for your responses to a previous full-board review of the study listed above. These responses are eligible for expedited review under OHRP (DHHS) and FDA guidelines. This is to confirm that I have approved your application.

Notify the HSC of any adverse events. Serious, unexpected adverse events must be reported in writing within 10 business days.

You may conduct your study as described in your application effective immediately. The study is subject to renewal on or before January 5, 2021, unless closed before that date.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Tom Bailey (208-282-2179; email humsubj@isu.edu) if you have any questions or require further information.

Sincerely,

Ralph Baergen, PhD, MPH, CIP
Human Subjects Chair

Dedication

This thesis is dedicated in loving memory of my parents, Austin A. and Rita M. Bell, who set me on the journey to become a dental hygienist. I will be forever grateful for their loving and steadfast devotion to each other and to our family, and for encouraging me to always keep reaching for my dreams.

Acknowledgement

I would like to express my deepest gratitude to my thesis committee members, Dr. Ellen J. Rogo and Dr. JoAnn Gurenlian for their endless support and flexibility, and for making this graduate experience so enriching. Dr. Rogo has mentored me beginning with my very first graduate course and continued to provided direction and expertise in the subject area of qualitative research throughout the thesis process. She has been an outstanding educator and role model in my graduate journey.

Dr. Gurenlian has guided me as my graduate advisor and mentored me as a role model throughout this graduate program as well as opened opportunities for me to be published. I will be forever grateful for her chair-side guidance, support, and presence for me in Cleveland.

I also want to acknowledge and thank Dr. Steven Moody for accepting the position as my graduate faculty representative and for providing valuable support and feedback.

I would like to thank my dear friend, Rita Menzies, who has been a valuable source of autism related knowledge, and who has shared with me an inside view of what it is like to be the parent and caregiver to a non-verbal son who has autism.

Finally, I want to thank my family. My husband, Ralph, for demonstrating what it means to be a true life partner, for his endless love and support, and for cheering me on through every step of my graduate experience. And, my daughters, Callie and Sage, thank you for your referrals, technical support and for your love and understanding as I pursued my graduate journey. I am forever grateful, thank you.

Table of Contents

List of Tables	ix
Abstract.....	x
Chapter 1 Introduction	1
Introduction.....	1
Statement of the Problem.....	4
Purpose of the Study	5
Professional Significance of the Study	5
Research Questions.....	6
Conceptual Definitions	7
Summary of Chapter 1	9
Chapter 2 Review of the Literature.....	10
Oral Health Status of Individuals with ASD.....	10
Provision of Oral Health Care for Individuals with ASD.....	31
Parents' and Children's Experiences Receiving Oral Health Care.....	50
Summary of Chapter 2	59
Chapter 3 Methodology	60
Research Design.....	60
Research Context	61
Research Participants	61
Sample Description.....	61

Human Subjects Protection.....	63
Data Collection	64
Instruments.....	64
Procedure and Protocols	64
Limitations	67
Statistical Analysis.....	67
Established Validity and Trustworthiness	68
Summary of Chapter 3	70
References.....	72
Title Page of Manuscript.....	82
Manuscript Abstract.....	83
Key Words: Autism spectrum disorder, young adults, qualitative, oral care, barriers to care, perception.....	83
Introduction.....	84
Methods.....	86
Results.....	88
Discussion	92
Conclusion	95
Acknowledgements.....	95
References.....	95

Appendix A – Recruitment Flier.....	108
Appendix B – Screening Questionnaire.....	109
Appendix C – Human Subjects Committee Informed Consent Form	110
Appendix D – Interview Guide.....	113
Appendix E – Request Letter	114
Appendix F – Thank You Letter	115
Appendix G- Confidentiality Agreement for Transcription Service	116
Security & Privacy at Rev	116
Storage & Transmission.....	116
Backup & Recovery	116
Availability & Access	116

List of Tables

Table 1 Emotional Experiences Related to Oral Health Care Visits	99
Table 2 Strategies that Oral Health Care Providers Use Participants Liked or Dislike.....	100
Table 3 Young Adults with ASD Responses to Communication Practices.....	102
Table 4 Oral Self-Care Recommendations Young Adults with ASD Like or Dislike	104
Table 5 Sensory Challenges Encountered When Seeking Oral Health Care	105
Table 6 Recommendations to Improve Oral Health Care Experiences	107

UNDERSTANDING ORAL CARE EXPERIENCES OF
YOUNG ADULTS WITH
AUTISM SPECTRUM DISORDER

Thesis Abstract – Idaho State University 2020

The purpose of this study was to understand the oral health care experiences of young adults who have autism spectrum disorder (ASD). A qualitative descriptive research design was used. Participants were recruited through purposive and snowball sampling procedures. Semi-structured interviews were performed and audio-recorded. Data were analyzed simultaneously with data collection. Fifteen individuals participated in the study; ten males and five females. Participants revealed a range of feelings related to their oral care experiences from positive to neutral to negative. Individuals reported that improvements in communication were needed; some did not wish to disclose their ASD diagnosis with their oral care providers. Multiple auditory, visual, and tactile sensory challenges were experienced. Additional research is needed to further explore this phenomenon from the perspective of those individuals with ASD who are non-verbal and from the experience of oral health care professionals who are working with young adults with developmental disabilities.

Key Words: autism spectrum disorder, young adults, qualitative, oral care, barriers to care, perception

Chapter 1 Introduction

Introduction

In the fifth edition of its *Diagnostic and Statistical Manual*, the American Psychiatric Association (APA) described autism as having previously been represented by four individual diagnoses consisting of autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger's syndrome (APA, 2013). In 2013 the APA merged these four categories into one diagnostic term of autism spectrum disorder (ASD). ASD is a persistent neurodevelopmental disorder with an early onset beginning in childhood with developmental delays appearing as early as 18 months or even younger with most diagnoses established between year 2 and 3 (Centers for Disease Control and Prevention [CDC], 2018).

The latest information reported by the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network (2018) was that the prevalence of ASD is 1 in 59 children over the 1 in 68 previously reported, and prevalence continues to be 5 times higher in males than females. In a 2018 report, ASD prevalence among US children, as provided by parents, was indicated to be 1 in 40 (Kogan et al., 2018). This increase in prevalence is thought to be a result of better diagnostic practices of broadening diagnostic criteria as well as children being diagnosed at younger ages (CDC, 2018; Kogan et al., 2018; Zwaigenbaum & Penner, 2018). Also considered in an increased prevalence of ASD is increased parent awareness; for the majority of cases the link or cause of ASD has been tied to genetics and tends to run in families (APA, 2013; Autism Speaks, 2018c). Finally noted were an increased risk when either parent was at an advanced age at time of conception, when there were pregnancy and birth complications before 26

weeks, low birth weight, multiple pregnancies, and pregnancies spaced less than a year apart (APA, 2013; Autism Speaks, 2018b; Kogan et al., 2018). Conversely, there was a decreased risk of ASD when prenatal vitamins containing folic acid were taken before conception, at conception, and throughout pregnancy; no risk of ASD was associated with vaccines (APA, 2013; Autism Speaks, 2018c). Over the last 30 to 40 years, Kogan et al. (2018) explained, the increase in diagnosed ASD had been rising globally and in the US.

Complex in nature, ASD is heterogeneous in that it has no link to race, ethnicity, or socioeconomic status. It was, however, described as having a core set of defining criteria or impairments associated with social interaction, speech and non-verbal communication, repetitive behaviors, and heightened sensory interests or sensitivities (APA, 2013; Autism Speaks, 2018c; National Institute of Health [NIH], 2015).

Intellectual disabilities with an intelligence quotient (IQ) of less than 70 were seen in 31% of children with ASD, 25% of children with ASD had an IQ of 71-85, and 44% of children with ASD had an above average IQ greater than 85 (APA, 2013; Autism Speaks, 2018a). Due to this complexity, individualized behavioral and educational interventions are necessary to guide each child or young adult with ASD through new and often unusual situations such as oral health care interventions.

Children and young adults with ASD pose a particular challenge to oral health care providers. Challenges related to ASD are a pervasive developmental disorder of the brain's normal development; impairments as seen in responding to social cues, communication activities, social interactions; and behavioral challenges (CDC, 2018).

Many children with ASD exhibit a lack of eye contact, language deficits, limited social interactions, repetitive behaviors, and urgency for routine (CDC, 2018).

For individuals with ASD who functioned in the moderate range of intellectual ability, holding a conversation or answering questions was limited. In a profound range, children with ASD may have self-injurious behaviors (SIB) or present greater difficulty with repetitive body motion (Stein et al., 2013). SIB were self-pinching, scratching, self-biting, or head banging. Oral SIB habits for children with ASD included bruxism, tongue thrusting, lip biting, and pica (Stein et al., 2013). Patients with ASD exhibited many challenges which necessitate the use of medications to control severe actions related to irritability, agitation, aggression, repetitive behaviors, delusions, and hallucinations (Loo, Graham, & Hughes, 2008). These challenges or impairments caused difficulties in the oral health care provider's ability to deliver oral care.

In addition, antipsychotic drugs used to control extreme behaviors often produced orofacial and systemic side effects (Loo et al., 2008). Systemic side effects from antipsychotic drugs presented many oral health challenges for individuals, while also affecting the oral health care provider's ability to deliver oral care (Loo et al., 2008). Side effects from ASD medications included xerostomia, hyper-salivation, difficulty swallowing, inflammation of the salivary glands, distortion of the sense of taste, inflammation of the mucous membrane, gingivitis, gingival enlargement, glossitis, bruxism, edema and discoloration of the tongue (Loo et al., 2008).

Also, research had shown that profound impairments and sensory sensitivities have had a direct relationship to behavior management in children with ASD (Stein, 2011). Profound impairments for individuals with ASD, such as, the ability to

communicate and participate in social relationships created additional challenges for oral health care providers (Stein, 2011). In addition, many oral health care providers lack experience on how to address these challenges effectively (Stein, 2011). The combination of heightened sensitivities and limited ability to communicate are reflected in children's and young adults' behavioral difficulties when undergoing oral health care. Little has been known about these patients' experience and perceptions while undergoing oral health care. In order to provide safe and quality care for children and young adults with ASD and learn about this population's perspective on oral care experiences, their voice needed to be heard.

This study explored the perspectives of young adults with ASD in regard to their oral health care experiences. One way to identify the range of perspectives, ideas, opinions, and feelings that people have about a topic was through in-depth interviews (Jacobsen, 2017). This type of interviewing promoted open-ended questions to delve into the individual's experiences and explore one's viewpoint. In-depth interviewing was utilized to gather perspectives of young adults with ASD, and attempted to discover attitudes, opinions, and points of view about oral health care delivery in an effort to improve their experiences.

Statement of the Problem

Young adults with ASD are members of a vulnerable population which have limited access to care (Brickhouse et al., 2009; Chi et al., 2016; Du et al., 2018). Few studies were conducted on the parent's perspective of their young adults' oral health care experience when the young adult has ASD, and none were published on these young adults' own perspectives of their oral health care experience. Most important, the results

of this study provided patients with ASD a voice. Understanding the perspective of young adults with ASD on their oral health care encounters has further developed the limited body of knowledge in this area. In an effort to improve oral health care for this vulnerable population, adaptations were made to the oral care provided to them through these learned experiences.

Purpose of the Study

The purpose of this qualitative study was to understand the oral health care experiences of young adults who have ASD in an oral health care setting.

Professional Significance of the Study

Researchers were tasked by the American Dental Hygienists' Association (ADHA) National Dental Hygiene Research Agenda (NDHRA, 2016), the Healthy People 2020 Objectives (2018a), the Institute of Medicine (IOM), and National Research Council of the National Academies (2011) to identify and study vulnerable populations in an effort to improve access to care. The outcome of this study advanced the ADHA NDHRA by addressing two of their primary objectives, Objective 1, which stated "To give visibility to research activities that enhance the profession's ability to promote the health and well-being of the public" (p. 3) and Objective 4, which stated "To stimulate progress toward meeting national health objectives" (p. 3). This study pertained to the NDHRA Conceptual Research Model, Population level, specifically access to care, and the phase of research was vulnerable populations. This research focuses on:

identifying populations that are challenged to achieve positive health outcomes including good oral health due to recognized and unrecognized barriers to care. Systems of health care delivery can be developed, adapted, improved and

evaluated for effectiveness in improving access to care and health outcomes in identified population. (p. 11)

Furthermore, this study was aligned to support the Healthy People 2020 Objective 6.3, to reduce the proportion of persons who were unable to obtain or delay in obtaining necessary dental care (U. S. Department of Health and Human Services [HHS], 2018a). This objective recognized the importance of being able to find a health care provider who will treat patients with ASD. Young adults with ASD can benefit from a professional relationship with their oral health care provider so that their oral health and communication needs are met.

Finally, this study was relevant to the Institute of Medicine and National Research Council of the National Academies (2011) stance *Improving Access to Oral Health Care for Vulnerable and Underserved Populations*. This publication outlined how poor oral health, especially for vulnerable populations, can lead to childhood speech problems, malnutrition, and significant, or potentially fatal, infections. Oral health care services for young adults with ASD are necessary to prevent oral and systemic disease.

Research Questions

The research questions that guided the conduct of this study were:

1. How would young adults with ASD describe their experiences of oral health care visits?
2. What strategies do young adults with ASD like or dislike that oral health care providers use to improve oral health care delivery for young adults with ASD?
3. How do young adults with ASD respond to various communication techniques presented by their oral health care provider when seeking oral health care?

4. What oral self-care recommendations do young adults with ASD like or dislike?
5. What are the challenges that young adults with ASD encounter when seeking oral health care?
6. What recommendations do young adults with ASD have to improve their oral health care experiences?

Conceptual Definitions

Autism spectrum disorder. ASD is defined by the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* as including autistic disorder, Asperger's disorder, childhood disintegrative disorder, and PDD-NOS (APA, 2018). ASD is characterized by a range of behaviors which manifests differently and to varying degrees; often seen are having "delayed learning of language; difficulty making eye contact or holding a conversation; difficulty with executive functioning, which relates to reasoning and planning; narrow, intense interests; poor motor skills' and sensory sensitivities" (APA, 2018; Autism Society, 2016, para 1).

Oral health care visit. An oral health care visit is synonymous with a dental visit and can be defined as an appointment or scheduled date for the purpose of receiving oral health care. Oral health care could consist of an oral examination, dental radiographs, an oral prophylaxis, restorative treatments, and oral self-care instructions (Colgate, 2018).

Strategies. Strategies are a mindful derived course of action with the intended purpose of achieving a goal (Merriam-Webster, 2018c). For the purpose of this study, strategies are the methods oral health care providers use, such as a fidget toy, a weighted

blanket, headphones, or sunglasses, to improve oral health care delivery for young adults with ASD.

Oral health care provider. An oral health care provider is synonymous with an oral health care professional who works to meet the oral health needs of the dental patient; examples of an oral health care professional are a dentist, a dental therapist, a dental hygienist, a dental assistant, and office support staff (Nunn, 2015). In this study an oral health care provider may be defined as an oral health care professional who provides oral health care.

Oral health care. Oral health care is defined as the intervention of oral health care services. Oral health care services are rendered through professional dental offices, clinics, universities, or hospitals. Oral health care services provide the treatments to bring about a level of oral health. According to *Healthy People 2020* oral health care strives to “prevent and control oral and craniofacial diseases, conditions, and injuries, and improve access to preventive services and dental care” (HHS, 2018b, para 1).

Communication technique. Communication technique is the way in which oral health care information and treatment is related to young adults with ASD.

Communication techniques can be with words, pictures, videos, or social stories.

Examples of communication techniques are “show, tell, and do,” picture exchange communication system (PECS), and social stories.

Oral self-care recommendations. Self-care: oral hygiene has been defined by the Nursing Outcomes Classification (NOC) as “the ability to care for one’s own mouth and teeth independently with or without assistive device” (self-care: oral hygiene, n.d., para 1). For the purpose of this study, oral self-care recommendations are the instructions,

such as frequency and technique of tooth brushing, flossing, and rinsing, to be followed by the young adult with ASD and potential caregiver to improve oral health care.

Challenges. Challenges are the difficulties encountered when trying to move forward with an activity (Merriam-Webster, 2018a). For the purpose of this study, challenges are the difficulties or the barriers that young adults with ASD encounter when seeking oral health care. One such challenge is finding a dental practice with the knowledge and skill level willing to treat patients with ASD (Brickhouse et al., 2009).

Recommendations. Recommendations are examples given on how to go about doing something such as a course of action to be followed (Merriam-Webster, 2018b). For the purpose of this study, recommendations will be the course of action young adults with ASD would like followed to improve their oral health care experience when oral health care is provided to them.

Summary of Chapter 1

ASD is a persistent neurodevelopmental disorder with an early onset beginning in childhood. Autism is known to affect 1 in 59 children with a five to one chance occurring higher in males. Limited studies existed reporting parent's perspective of their autistic child's experiences with oral health care delivery; however, no research of young adults with ASD existed describing their oral health care experiences. The next chapter reviewed the pertinent literature.

Chapter 2 Review of the Literature

A literature review was conducted to examine previous research regarding relationships between ASD and oral health care experience, including unmet dental needs, barriers to oral care, oral health status, anxiety, as well as oral health care as it relates to the parent's and caregiver's perception of the child's and young adult's experience. Databases utilized included: PubMed, Google Scholar, EBSCOhost, and CINAHL Complete. The following MeSH description, or combinations of search terms were used: caregivers, autism, oral health, oral care, communication, qualitative, and dental. The search was limited to English, full text, scholarly journal articles from the years 2007-2018. The following sections were included in this literature review: oral health status of individuals with ASD, provision of oral health care to patients with ASD, and parent's and adolescents' experiences receiving oral health care.

Oral Health Status of Individuals with ASD

Oral health status was important for individuals with ASD. Individuals with ASD are part of a vulnerable population with behavioral impairments, which can lead to challenges in oral care. Behavioral impairments such as difficulty with communication, impaired social interactions, restricted interests, eating habits, resistance to oral care, and repetitive and stereotyped behaviors can influence an individual's oral health status (APA, 2013). In addition, these impairments can present challenges for the oral health care provider's delivery of oral health care in adolescents and young adults with ASD, and also present challenges by the way the patient responds to this care. Furthermore, these challenges' impact on oral health care can increase the risk of oral diseases such as dental caries and periodontal disease. Dental caries risk was thought to increase for

individuals with ASD when they are exposed to carbohydrate dense foods, added sugars, and between meal snacking accompanied with non-nutritive chewing and inadequate oral self-care (El Khatib et al., 2014). Still, there was conflicting evidence on the oral health status of adolescents and young adults with ASD and dental caries. Some studies have found caries prevalence to be lower in children with ASD, which was explained by parent reported lack of snacking preference due to food selectivity or sensory sensitivities (Du, et al., 2018; Loo et al., 2008). Other studies have shown there to be no significant difference in caries prevalence when comparing children with ASD and typically developing (TD) children (El Khatib et al., 2014). However, still other studies agreed ASD posed a great risk of oral disease (da Silva et al., 2017). The following paragraphs highlight studies regarding the oral health status of children and young adults with ASD and presented possible reasons for the controversy related to dental caries and periodontal health.

“Oral health is integral to general health and quality of life, and basic oral health services are an essential component to primary health care” (Loo et al., 2008, p. 1524). The Oral Health-Related Quality of Life (OHRQL) Model for Dental Hygiene was focused on quality of life connected to the importance of overall health (Gadbury-Amyot et al., 2018; Williams et al., 1998). With this theoretical model in mind, researchers, in 2008, studied the caries experience and behavior of patients with ASD and compared these characteristics with those in a group of TD individuals by means of a cross-sectional analysis (Loo et al., 2008). A control group of 386 children was randomly selected from the same population of dental patients at Franciscan Hospital for Children (FHFC) in Boston (Loo et al., 2008). The control group required dental care; however,

they did not have any medical conditions nor were they prescribed any medications (Loo et al., 2008). Dental care addressed caries prevalence (sum of primary decayed and filled teeth [dft] and sum of permanent decayed, missing and filled teeth [DMFT] greater than 0), which was defined as proportion of patients with a positive dental caries experience (Loo et al., 2008). Data recorded included patient behavior by means of the Frankl scale (Loo et al., 2008), as well as whether patients resided in private homes as opposed to institutional or group home facilities; whether they had ASD as a primary diagnosis; and whether they had a history of seizure disorder (Loo et al., 2008). ASD patients with comorbidities who were significantly older than other ASD patients who did not have comorbidities showed no significant difference in DMFT scores (Loo et al., 2008).

Demographic results for gender within the ASD group was 317 males to 78 females or 4:1 (Loo et al., 2008). The control or unaffected group was evenly balanced with 193 males and 193 females (Loo et al., 2008). The ASD group had a lower caries prevalence ($P < .0001$) than the control group, as shown by the finding that 68.1% of the ASD group had a positive dental caries history compared to the control group of 86.0% (Loo et al., 2008). Also, the caries severity of patients in the ASD group was significantly lower than the control group (Loo et al., 2008). Possible rationale for lower caries prevalence and severity in patients with ASD could be contributed to a less cariogenic diet and good home care by the patients' parents (Loo et al., 2008). Also, noted was children with ASD were less partial to sweets, more regular in their behavior at meals, and less likely to snack (Loo et al., 2008). Still, oral health care providers were tasked to stress the importance of routine preventive oral self-care and dietary choices because sweet foods may be used for behavioral compliance activities (Loo et al., 2008).

Finally, results indicated that caries prevalence and severity did not vary between patients who were institutionalized and not institutionalized, nor among the different ASD diagnosis groups, nor with the use of psychotropic medications, presence of seizure disorder or additional diagnosis (Loo et al., 2008).

However, when measuring for behavior, ASD patients often required the use of general anesthesia (GA) for restorative dentistry as they were found to be significantly more uncooperative than the control group (Loo et al., 2008). The researchers noted of the 187 patients in the ASD group, 47.3% were prescribed medication, 45.5% of these patients took two or more medications, and 41.2% were receiving antipsychotic drugs to manage ASD symptoms (Loo et al., 2008). ASD symptoms consisted of, but were not limited to, irritability, agitation, self-injurious behavior, aggression, repetitive behaviors, delusions, and hallucinations, all of which necessitated the use of GA to completed restorative oral health care (Loo et al., 2008). Also, pointed out were adverse interactions from antipsychotic drug use. Orofacial and systemic side effects commonly resulted from ASD medications include dry mouth (xerostomia), hyper-salivation (sialorrhea), difficulty swallowing (dysphagia), inflammation of a salivary gland (sialadenitis), distortion of the sense of taste (dysgeusia), inflammation of the mucous membrane (stomatitis), gingivitis, gingival enlargement, glossitis, bruxism, edema and discoloration of the tongue all of which affected the oral health status of the ASD patient (Loo et al., 2008). Limitations of this study included inconsistent ASD diagnoses from parent reports, varied oral healthcare providers administering treatment, and lack of measurements for socioeconomic status (Loo et al., 2008). Socioeconomic status was commonly related as a determinant of caries prevalence and severity (Loo et al., 2008).

Similarly, children with ASD typically presented with poorer oral hygiene and condition of the gingiva than TD children according to one such case-control study from 2009 to 2011 (El Khatib et al., 2014). Egyptian researchers analyzed the oral health status and behavior in children with ASD compared to TD children (El Khatib et al., 2014). One hundred children with ASD and a control group of 100 TD children were recruited from private and governmental institutions of intellectually disabled and private governmental schools respectively (El Khatib et al., 2014). The study group and control group were children from age 3 to 13 years and matched for age, gender, and socio-economic status (El Khatib et al., 2014).

Questionnaires were utilized to gather data about family socio-demographic information, medical and dental histories of children with ASD, dietary habits, caregiver prediction of child's cooperation during oral examination, parent prediction, and acceptance of behavior management techniques (El Khatib et al., 2014). In addition, data collected were habits of self-injurious behavior and other oral habits including bruxism, tongue thrusting, lip biting, and pica (El Khatib et al., 2014). One examiner conducted all the clinical examinations in the presence of the child's teacher after consent was attained using the 'Tell-Show-Feel and Do' technique (El Khatib et al., 2014).

Included in the examinations were the child's behavior assessment measured with the Frankl Behavioural Rating Scale, an extraoral examination to identify self-injurious behaviors, and an intraoral examination (El Khatib et al., 2014). The intraoral examination assessed oral hygiene condition, gingival condition, caries prevalence and experience, bruxism, and oral injuries (El Khatib et al., 2014).

The statistical package for social services (SPSS) version 16.0 was utilized for data analysis with a significance level set at $p=.05$ (El Khatib et al., 2014). The results showed no statistically significant difference in the parental education or level of sociodemographic data between the two groups (El Khatib et al., 2014). However, dental histories documented fewer dental visits ($p=0.002$) in the previous year and more difficulty finding a dentist ($p<0.0001$) willing to care for children with ASD than TD children (El Khatib et al., 2014). Furthermore, less children with ASD brushed their teeth or used fluoridated tooth paste than TD children (El Khatib et al., 2014). More children with ASD had tooth brushing problems and required supervised tooth brushing than TD children (El Khatib et al., 2014).

In addition, no differences were found in snacking habits or frequency of snacking; however, differences were noted by snack preference where less children with ASD preferred fruits and sweets (El Khatib et al., 2014). Also, significantly more children with ASD had problems with self-injurious behavior (SIB) as well as a prevalence of non-nutritive chewing, swallowing, and drooling of saliva (El Khatib et al., 2014). Noted was a statistically significant difference between the behavior guidance techniques preferred by the parents in the two groups, where parents of children with ASD were more accepting of GA and parents of TD children were more accepting of “Tell Show and Do” (El Khatib et al., 2014). In the same manner, children with ASD showed statistically significant differences in mean plaque and gingival indices, thereby having more plaque and worse gingival condition than TD children (El Khatib et al., 2014).

Finally, when comparing the two groups' primary, mixed, and permanent dentitions, there were no significant differences in caries prevalence or in mean caries experience, whereas there was a statistical significant difference for children with ASD in the mean number of filled primary teeth compared to TD children (El Khatib et al., 2014). Furthermore in mixed dentitions, children with ASD had significantly more carious primary teeth and less restored primary teeth than TD children (El Khatib et al., 2014). This last difference was attributed to children with ASD behaving negatively and exhibiting uncooperative tendencies during oral care visits (El Khatib et al., 2014).

Similarly, in a case control study, Onol and Kirzioglu (2018) conducted research on the oral health status and influential factors in children with autism living in the Western Mediterranean Region of Turkey. Utilizing a cross-sectional study of both a questionnaire and interview process, 332 questionnaires were sent to parents of children with ASD with 126 returned completely filled out and evaluated (Onol & Kirzioglu, 2017). Questionnaires for a control group of 111 children without ASD were included in the study (Onol & Kirzioglu, 2017). Also, oral examinations of 111 control children and 63 children with ASD were performed (Onol & Kirzioglu, 2017). Results of the study revealed 29.4% of children with ASD never brushed their teeth and 36.5% only brushed their teeth sometimes (Onol & Kirzioglu, 2018). Self-brushing was 4.8% for children with ASD and 75.7% for children without ASD (Onol & Kirzioglu, 2018). As for periodontal status, when compared to children without ASD, children with ASD were found to have a higher plaque index and gingival index which was statistically significant (Onol & Kirzioglu, 2017). In addition, 18.3 % of children with ASD exhibited poor oral habits of retaining food in their mouths, self-injurious habits were reported for 16.7%,

and children with ASD were also reported to have a higher number of cases of bruxism and occlusal disharmonies (Onol & Kirzioglu, 2018). Conclusions for this study indicated that eating habits and retaining food in the mouth related to the significance of a higher rate for decayed, missing, and filled teeth for the children with ASD in addition to inadequate personal oral care and periodontal disease (Onol & Kirzioglu, 2018).

At the same time, in 2017, Brazilian researchers conducted a systematic review and meta-analysis on studies published up to the last day of 2015 with a focus on the prevalence of dental caries and periodontal disease in primarily children and young adults with ASD (da Silva et al., 2017). A total of 928 articles were screened of which 7 articles satisfied the eligibility criteria (da Silva et al., 2017). To meet eligibility criteria, articles had to address the oral health status of individuals with ASD and the selected research had to be cross-sectional or longitudinal (da Silva et al., 2017). In addition, dental caries were assessed as lesions, at any phase of development, from white spots to cavitation, whereas periodontal disease was characterized as any deviation from normality (da Silva et al., 2017). The overall trend of the meta-analysis pertaining to the prevalence of dental caries was 60.6% (95% CI: 44.0 – 75.1), whereas the trend pertaining to the prevalence of periodontal disease was 69.4% (95% CI: 47.6 - 85.0) (da Silva et al., 2017). Only two of the seven studies assessed sugar exposure which was an important factor in caries risk assessment (da Silva et al., 2017).

Based on the 2010 WHO targeted goal of 90% caries free for 5-year-old children and the goal of DMFT <1 for 12-year-olds, this systemic review concluded that the prevalence of dental caries was high for individuals with ASD (da Silva et al., 2017). In contrast, the studies for periodontal disease assessed only three studies, presented a wide

confidence interval, lacked a standardized index, and collected data ranging from gingivitis to periodontal disease, thereby limiting this portion of the study to possible overestimates (da Silva et al., 2017). The researchers concluded that dental caries and periodontal disease in children and young adults with ASD was considered high, whereas previous studies have shown conflicting results of caries and periodontal disease incidence for these individuals (da Silva et al., 2017). Finally, the researchers made the following conclusions: that a higher prevalence of periodontal disease and dental caries in individuals with ASD had a strong association with a cariogenic diet as well as limited caregiver and/or self-care oral hygiene practices. Furthermore, the rate of dental caries and periodontal disease was higher in this vulnerable population, thereby influencing their oral health status (da Silva et al., 2017).

Likewise, Morales-Chávez (2017) conducted an observational, transversal study with 96 pediatric patients with autism. Dental care was provided by dentists who specialized in children with special needs; specifically studied were children with autism by age (Morales-Chávez, 2017). Morales-Chávez reported the caries prevalence in the two to six year-old group was 35.5% (n=45), the seven to 11 year old group was 46.6% (n=45), and the 12 to 16 year-old group was 50% (n=6). Overall, 41.7% of the children had a presence of caries (Morales-Chávez, 2017). Similar to the systematic review results, the Morales-Chávez study results contradicted previous studies and claimed caries prevalence was higher in children with ASD.

In conclusion, each of these aforementioned studies showed that there was conflicting evidence on the oral health status of children and young adults with ASD. Loo et al. (2008) maintained that a caries history of 70.5% was less likely in patients with

ASD compared to their TD counterparts; moreover, children with ASD younger than 6 were 83.4% less likely to have a positive caries experience, and children with ASD 6 to 17 years were 65.9% less likely to have a positive caries experience. Still, El Khatib et al. (2014) pointed out that in a mixed dentition, children with ASD had significantly more carious primary teeth and less filled primary teeth than TD children. This difference related to children with ASD behaving negatively and exhibiting uncooperative tendencies during oral care visits (El Khatib et al., 2014). In addition, Onol and Kirzioglu (2017) summarized that children with ASD had a higher plaque index and gingival index. These researchers concluded that eating habits and retaining food in the mouth related to the significance of a higher rate for decayed, missing, and filled teeth for the children with ASD in addition to inadequate personal oral care and periodontal disease (Onol & Kirzioglu, 2017). Finally, the systematic review and meta-analysis, based mostly on non-US studies, acknowledged dental caries and periodontal diseases was considered high in children and young adults with ASD even though previous studies have shown conflicting results of caries and periodontal disease incidence for these individuals (da Silva et al., 2017); likewise Morales-Chávez (2017) agreed that a caries prevalence was higher in children with ASD

Unmet dental needs. Oral health status for children and young adults with ASD was also influenced by unmet dental needs; unmet dental needs are described by the American Academy of Pediatric Dentistry as not having routine dental care for more than a year. These unmet dental needs resulted from a low household income, lack of insurance, poor oral health literacy, and lack of willingness of dentists to treat children with special health care needs. Contributing to the difficulty of finding a dentist willing to

provide care for this population was children and young adults with ASD had more aversions to dental care and had more treatment complications posed by their medical condition. Children and young adults with ASD were considered a vulnerable population and, as such, were faced with barriers to oral health care which can contribute to a less than optimal oral health status from these unmet needs.

In a 2009 study in Virginia, researchers addressed how families with autistic children accessed oral health care and identified the barriers which interfered with this access (Brickhouse et al., 2009). Family reported barriers included: their child's limited ability to communicate, their child's extreme concern towards new people or settings, dental staff ineptitude in serving disabled children, a need for sedation, inability to find a Medicaid dental office, and difficulty finding a dental practice willing to treat patients with autism (Brickhouse et al., 2009).

A questionnaire was mailed to all families (n=200) who were signed up with The Autism Program of Virginia (TAPVA) and cared for at least 1 ASD child (Brickhouse et al., 2009). The questionnaire consisted of five dental access designed questions pertaining to a child's last visit, presence of a dental home, a next visit scheduled within 12 months, an incident causing an inability to access a needed visit, and experience of being refused dental care (Brickhouse et al., 2009).

The data collection overall response rate was 29 percent (n=55) of the 200 questionnaires mailed to participants (Brickhouse et al., 2009). Data analysis was conducted with Pearson's chi-square and Fisher's exact tests which measured the connection between the child's ASD diagnosis, insurance coverage, age, race, education, and past behavior in dental offices to the five dental care access measures (Brickhouse et

al., 2009). Socioeconomic factors and history of treatment behavior were significantly related to the dental care access measure of time since last dental visit (Brickhouse et al., 2009). Education, income, insurance coverage, and treatment behavior history were significantly related to having a dentist for periodic dental care (Brickhouse et al., 2009).

The results of the five dental care access measures were assessed by a multivariate regression analysis where elements that had $p < .10$ were considered autonomously significant in relation to a child's ability to access care (Brickhouse et al., 2009). Two of the dental care access measures showed significance: first was the child's history of oral health treatment behavior and second was family income (Brickhouse et al., 2009). Children with better behavior and higher family income had improved ability to access oral health care. In the past 12 months for this study, Brickhouse et al. (2009) reported unmet dental need of 19% for children with ASD.

Possible limitations to the study suggested were the low 29% response rate being due to the survey length as well as the mailing list derived from TAPVA may attract families with a higher socioeconomic status who would be more inclined to seek out services for their children with ASD and thereby underrepresent barriers to dental care (Brickhouse et al., 2009). From this study, the authors concluded that children with ASD who exhibited uncooperative behaviors were significantly more likely to have limited access to dental care and to have a limited ability to receive care when needed (Brickhouse et al., 2009). Furthermore, children were significantly less likely to have a dental home and access to needed dental care when family income was \$20,000 to \$49,000 (Brickhouse et al., 2009). Finally, 24% of ASD children did not have a dental home due to not finding dental practitioners with training or fortitude to serve this

population (Brickhouse et al., 2009). Not having a dental home was a barrier to oral health care which was synonymous with having unmet dental need.

Similarly, Lai et al. (2012) explored the subject of unmet dental needs and contributing factors which block access to treatment among children with ASD. The focus of this study delved into children with ASD's unmet dental needs and related barriers to oral health care, and further related this information to the child's type of diagnosed ASD and the child's oral health treatment behavior (Lai et al., 2012). The study was conducted from March to May of 2010. Surveys were sent to 1,500 families listed in the Autism Registry of North Carolina who met the inclusion criteria having one or more children age 18 and under who were diagnosed with ASD (Lai et al., 2012). The main question asked to determine the presence of unmet dental need in children with ASD was "During the past 6 months was there a time when you wanted to get dental care for your child but could not get it at that time?" (Lai et al., 2012, p. 1296). A bivariate analysis of the Fisher's exact test was used to analyze the affiliation between the dependent and independent variables (Lai et al., 2012). Comparable to other studies, the main barriers to oral health care were related to the child's behavior (60%), the cost of care (38.5%), and the lack of dental insurance (23.1%) for this population with ASD (Lai et al., 2012). When comparing unmet dental needs in the past 6 months, Lai et al. noted 12% for children with ASD as compared to Brickhouse et al.'s (2009) report of 19% over a 12-month period.

Furthermore, in 2014, McKinney et al. conducted a transverse study to measure the prevalence of unmet dental needs and analyzed the related factors for unmet dental need from a national sample of children with ASD. The study population was selected by

random telephone calls from the Center for Disease Control and Prevention's National Center for Health Statistics National Survey of Children with Special Health Care Needs (NS-CSHCN) listing (McKinney et al., 2014). To determine the child's potential eligibility as CSHCN parents were asked five screening questions. After screening 372,698 children nationally, 40,242 children were found to have unmet dental need and of these children, 2772 children met the criteria for ASD and were between the ages of 5 through 17 (McKinney et al., 2014). The outcome measures were described as all classes of unmet oral health care need based on the child not receiving all preventive dental care needs or all other dental care needs during the past 12 month period (McKinney et al., 2014). The prevalence of unmet dental needs for children 5 to 17 years of age with ASD was 15.1% (95% CI, 12.3% - 18.4%) of which an inordinate number were from a household near or below the federal poverty level, on Medicaid, or uninsured (McKinney et al., 2014). In addition, having an intellectual disability had a positive association with unmet dental need as did having a gap in insurance. Not having a medical home was the strongest predictor (adjusted odds ratio [aOR], 4.46; 95% CI, 2.59 - 7.69) of unmet dental need (McKinney et al., 2014). Also noted were behavioral difficulties, communication, and physical function difficulties as predictors of increased unmet dental need, even though parent reported ASD severity, anxiety, ADHD, and special education services were not associated with having unmet dental need (McKinney et al., 2014). Notably, the most parent-reported barrier to receiving all needed dental care for children with ASD was cost (McKinney et al., 2014).

In 2018, researchers in Hong Kong conducted a case-control study to compare 3- to 5- year old children with ASD to children without ASD on their level of behavior

during oral care and their barriers to this care (Du et al., 2018). This study compared the parents' level of dental understanding and their perception of the dental care experience for each group of children (Du et al., 2018). Participants were randomly selected from 19 of 34 identified Special Child Care Centers (SCCC) in which 515 parents responded positively to participation along with a control group from conventional preschools that were matched for age and gender (Du et al., 2018). Of the 515 children with ASD recruited from SCCC, 257 children participated where 217 were male (84%) and 40 were female with a control group (257) matched for age and gender (Du et al., 2018).

Data collection focused on the child's oral health behaviors, barriers to dental services, oral health knowledge, and oral health attitudes (Du et al., 2018). Children with and without ASD were assessed on oral care practices and habits of brushing frequency, self-care assistance, use of products, and between meal snacking (Du et al., 2018). Barriers to oral self-care analyzed were brushing difficulties and the reasons for tooth brushing difficulties, whereas barriers to dental care focused on were those stemming from the dental practice or those stemming from the family demographics and from the child (Du et al., 2018). The parent's oral health knowledge was measured through a series of questions regarding their understanding of and prevention of caries and periodontal disease (Du et al., 2018). A second set of question (true or false) were generated for parents to rate as agreeing or disagreeing with to measure oral health attitude (Du et al., 2018).

Results revealed significant differences in reported oral health behaviors of preschool children with and without ASD (Du et al., 2018). ASD children had lower frequency of tooth brushing, greater frequency of brushing assistance, less toothpaste

usage, less between meal snacking, and more cases of dental care under GA (Du et al., 2018). In addition, parents reported that their children with ASD had difficulties executing oral care practices, and an inability to hold still for oral health care procedures (Du et al., 2018). For children with ASD, challenges of going to the dentist were pointed out to be both for environmental and non-environmental reasons (Du et al., 2018). Solutions recommended for these challenges were to have more training programs available for dental practitioners, develop behavioral interventions such as tooth-brushing social stories for children, and oral desensitizing (Du et al., 2018). The parents of children with ASD showed an increased oral health care knowledge for both causes and prevention of periodontal disease and dental caries as well as higher overall oral health attitude scores (Du et al., 2018).

Another barrier contributing to unmet oral health needs is health care providers' (HCP) lack of collaboration to initiate interprofessional dental referrals. In 2015, Murshid conducted a study which assessed the dental knowledge of educators and health care providers working with children with ASD. A cross-sectional survey was conducted at special-needs centers within the community of Riyadh, Saudi Arabia from September to November 2014 (Murshid, 2015). A voluntary self-administered survey (n=217) was collected from a group of educators and special-needs care providers who worked with children diagnosed with ASD (Murshid, 2015). The specialties of the surveyed group consisted of speech therapists, training/play therapists, special-needs educators, teachers in merging classes, sociologists, nutritionists, psychologists, trainee or students, and volunteers (Murshid, 2015). The survey questions focused on the dependent variable of dental knowledge and attitude of HCP (Murshid, 2015). The questions were constructed

from preventive dental measures, such as counseling parents on oral hygiene, suggesting parents pursue dental checkups, performing visual examinations of the oral cavity and teeth to make referrals, recommending age of first dental visit and counting the number of tooth brushing per day, assessing conflicts encountered with tooth brushing, acknowledging persons responsible for child's oral hygiene, evaluating sources of dental knowledge, and acknowledging the main cause of dental caries (Murshid, 2015). The researchers found that 49.8% of the participants did not provide recommendations to parents of children with ASD regarding tooth brushing need, 73.3% never recommended parents pursue dental checkups, and 75.6% never conducted visual examinations of the oral cavity and teeth for children who were under their care to make referral recommendations (Murshid, 2015). In conclusion, the researchers pointed out that the HCP were directed towards medical and educational aspects of care and neglected to include an oral health focus (Murshid, 2015). Almost half of the study participants failed to indicate the importance of oral hygiene to family members of children with ASD; they neither emphasized the need to brush one's teeth nor did they initiate a referral to their dental colleagues (Murshid, 2015). The researcher explained the need for oral health care providers to educate their colleagues on appropriate and specific dental knowledge designed for children with ASD (Murshid, 2015).

Furthermore, another barrier contributing to unmet dental needs was not having a dental home. In a US based longitudinal analysis from 2002 to 2011 researchers studied dental homes for children with autism to answer two study goals; (1) to analyze preventive oral health care and dental home utilization rates for Medicaid-enrolled children by ASD status; and (2) to examine the breadth to which I-Smile affected ASD-

related disparities in dental utilization (Chi et al., 2016). The study population was Medicaid-enrolled children (n=30,059) aged 3 to 17 years. The 9 cohort years were divided into three I-Smile periods: pre-implementation, initial implementation, and maturation which aligned with the years 2003-2005, 2006-2008, and 2009-2011 respectively (Chi et al., 2016). The researchers conjectured that newly Medicaid-enrolled children with ASD were less likely to have dental homes and less likely to seek preventive oral health care than newly Medicaid-enrolled children without ASD (Chi et al., 2016).

Contrary to previous study results regarding dental homes, 8% of the 30,059 children had a dental home, 9.8% (n=408) of children with ASD had a dental home (95% CI=7.3%, 14.1%) and 8.0% of children without ASD had a dental home (95% CI=7.8%, 8.3%) (Chi et al., 2016). Furthermore 36.3% (95% CI=31.8%, 41.3%) of children with ASD utilized preventive oral health care in comparison to 45.7% (95% CI=45.1%, 46.3%) of children without ASD (Chi et al., 2016). Although not statistically significant, children with ASD were more likely to have a dental home across all years of the study (Chi et al., 2016). When examining the pre-implementation (2003-2005), and initial implementation (2006-2008) periods, children with ASD were less likely to have a dental home, yet during the later maturation period children with ASD were more likely to have a dental home (Chi et al., 2016). Overall throughout the study periods children with ASD were less likely (RR=0.79, 95% CI=0.70, 0.91, $p<0.001$) to utilize oral health care services (Chi et al., 2016). By 2009-2011, children with ASD were significantly less likely (RR=0.74, 95% CI=0.63, 0.86, $p<0.001$) to utilize oral health care services (Chi et al., 2016).

To summarize, these studies showed barriers to dental care were the major reason for unmet dental needs which has an impact on oral health status. Brickhouse et al., (2009) presented the argument that when children with ASD have unmet dental needs their oral health status is also affected. These researchers concluded that 6% to 7% of children in the general population had unmet dental needs, whereas in Virginia, 30% of ASD children had unmet dental needs, and in Alabama, 27% of special needs children had unmet dental needs (Brickhouse et al., 2009). These needs increased for children with ASD when uncooperative behaviors limited treatment completion and the ability to find an oral health care provider willing to treat this population (Brickhouse et al., 2009). In addition to Brickhouse et al.'s study, Lai et al., (2012) concluded that 11% of children had unmet dental needs and cited the reasons as the child's lack of cooperation, the cost of dental care, and the absence of dental insurance. In the same manner, McKinney et al., (2014) indicated 15% of children with ASD ages 5 to 17 years had unmet dental needs. This study concluded the strongest indicators for having unmet dental needs were not having a medical or dental home and the cost of care (McKinney et al., 2014). Contrary to this argument, Chi et al (2016) established that many children with ASD had dental homes, yet for undisclosed reasons failed to utilize the services of these dental homes. A gap in insurance was cited as an indicator for unmet dental needs, whereas anxiety and attention deficit disorder were not associated with unmet dental needs (McKinney et al., 2014). Finally, barriers for children with ASD were more frequently reported, even though Du et al. (2018) acknowledged parents of children with ASD had better knowledge and attitudes regarding oral health.

Anxiety. Oral health status for children and young adults with ASD was also affected by anxiety. Anxiety can trigger overt behaviors in children and young adults with ASD who exhibit limited communication skills to express oral care experiences making dental procedures difficult to complete. Overt or uncooperative behaviors associated with autism may include hyperactivity, quick frustration, shortened attention span, impulsivity, agitation, anger, self-stimulatory, self-injurious, repetitive, aggressive, and disruptive behaviors all which have an effect on the patient's oral health status. Each of these behaviors made oral health care delivery challenging. By reducing environmental stimulus in the dental environment, patients with ASD could potentially cooperate better and have less anxiety for their dental procedures.

In a study involving forty-four children, 22 with a diagnosis of ASD and 22 TD, from current and past Children's Hospital Los Angeles (CHLA) dental clinic patients, a Sensory Adapted Dental Environment (SADE) was utilized to compare the two groups after two dental hygiene prophylaxis (Stein et al., 2014). Electrodermal activity (EDA) was used to analyze physiological stress and anxiety in which both a base line and dental hygiene prophylaxis segments were measured (Stein et al., 2014). As foreseen, ASD and TD groups demonstrated significantly different child-descriptor variables (Stein et al., 2014). Communication skills were significantly lower in ASD children compared to TD children (Stein et al., 2014). As reported by parents, children with ASD had significantly more difficulties with sensory processing, general anxiety, and dental anxiety ($p < .001$ for all variables) than did TD children (Stein et al., 2014). During oral care dentists reported children with ASD displayed increased overt behavioral distress by presenting greater uncooperative behavior and a higher incidence of needing restraint 73% ($n=16$)

compared to 9% (n=2) for TD children (Stein et al., 2014). Consistent with previous research, this study found that children with ASD demonstrated significantly more uncooperative behaviors during regular oral hygiene prophylaxis appointments compared to TD children (Stein et al., 2014). The researchers concluded that physiological stress and overt behavioral distress in children with ASD were significantly correlated; as dental procedural stress (physiological stress) increases, uncooperative behavior (behavioral distress) also increases (Stein et al., 2014).

During the same time, researchers in Stockholm studied the experiences of dental care and dental anxiety in adults with ASD. Using self-reporting questionnaires for the study approach, Blomqvist et al. (2014) measured negative dental experiences as well as the two group's level of dental anxiety by comparing adult patients with ASD to a matched TD control group. A total of 116 adults (47 adults with ASD and 69 TD adults) participated in the study (Blomqvist et al., 2014). The Corah Dental Anxiety Scale, the Dental Anxiety Scale, and the Revised Dental Beliefs Survey were used to measure previous dental experiences, dental anxiety of anticipated dental treatment, and perceived clinician's behavior and trustworthiness (Blomqvist et al., 2014). Results of previous dental experiences revealed about 22% of adults with ASD had "feeling of being forced to dental treatment one was not prepared for" compared to 3% of TD adult patients (Blomqvist, 2014, p. 5). Next, more dental anxiety was reported by the ASD group 7/47(15%) compared to 4/69 (6%) for the TD group (Blomqvist et al., 2014). Finally, in the Dental Beliefs Survey, ranked first was "When the dentist seems in a hurry I worry that I am not getting good care" and ranked second was "Once I am in the chair I feel helpless (that things are out of my control)" (Blomqvist, 2014, p. 6). The researchers

concluded that patients with ASD reported increased pain with dental procedures, more dental anxiety, and frequently felt they were being subjected to dental treatment they were not prepared to undergo (Blomqvist et al., 2014).

To summarize, researchers have shown that the oral health status in children and young adults with ASD was affected by the many characteristics associated with autism. Anxiety was only one stressor patients with autism experience when receiving oral health care. Individuals with autism often display differing levels of behavioral and communication impairments which also contributed to the difficulty with oral self-care and oral health care delivery. These impairments contributed to the barriers which prevent access to care and add to this population's unmet dental needs. In spite of the conflicting evidence on caries prevalence and caries history in children and young adults with ASD, researchers agreed that cost of dental care, gaps in insurance, lack of a medical and/or a dental home was paramount in affecting the oral health status of children and young adults with ASD. Furthermore, oral health care providers were key players in assessing the needs of their patients with ASD and providing the appropriate environment for their patients with ASD. The next section of this literature review focused on matters associated with treating individuals with ASD. It addressed providers' experiences and challenges in providing an appropriate environment for treatment of oral health care, methods to communicate the delivery of oral health care, and strategies to foster behavioral compliance when treating individuals with ASD.

Provision of Oral Health Care for Individuals with ASD

Individuals with ASD were part of a population with a high prevalence of sensory processing difficulties. When faced with oral health care visits, much has been studied

about sensory processing issues, communication techniques, and behavioral management experiences for children with ASD (Chandrashekhar & Bommangoudar, 2018; Elmore, et al., 2016; Stein et al., 2013). Regular sensory characteristics of the oral health care visit, such as glaring florescent lights, moving back in the chair, touching in the mouth especially the tongue, and tasting and smelling of oral care products trigger such children with ASD to react with anxiety and uncooperative behaviors (Stein et al., 2013). Furthermore, many children with ASD had an inability to make eye contact and to interact with less familiar individuals, including oral health care providers, which contributed to less than optimal communication with these children (Stein et al., 2013).

Kuhaneck and Chisholm (2012) produced a paper for the purpose of improving dental visits for individuals with ASD through an understanding of sensory processing. Sensory processing was explained as the way the nervous system processes internal and external sensations with an expected behavioral response; however, individuals with ASD who experience sensory defensiveness or processing difficulties had exaggerated reactions (often negative) to stimuli that individuals without ASD usually find bearable (Kuhaneck & Chisholm, 2012). Exaggerated reaction to tactile, vestibular, auditory, visual, proprioceptive, gustatory, and olfactory sensations varied tremendously from one person with ASD to the next person with ASD (Kuhaneck & Chisholm, 2012). Frequently children and young adults with ASD responded to sensory processing difficulties by acting out or trying to escape in a “fight or flight” response (Kuhaneck & Chisholm, 2012, p. 230). Acting out varied in a wide array of probable behaviors from gazing away or physically hiding, to pulling away, crying, and blocking of stimuli with hands and arms, to more intense behaviors such as hitting, kicking, biting, or pushing

(Kuhaneck & Chisholm, 2012). All of these behaviors had an impact on the delivery of oral health care.

Kuhaneck and Chisholm (2012) discussed sensory processing for the patient with ASD and the oral health care visit; the authors explained how oral health care providers need to be aware of the many stimuli that occur during oral health care; and they pointed out the necessity to be able to recognize behaviors as a result of those stimuli. The researchers explained reactions to touch consisted of over-sensitivity to the oral prophylaxis, overreaction to surprising contact to the face or mouth, intense dislike of texture and grittiness of the polishing paste, and unexpected responses to dental instruments, x-ray devices, or gloved hands (Kuhaneck & Chisholm, 2012). Next, they explained how a reaction to motion was exhibited by an acute fear response to the reclining of the dental chair where the sensation of moving backwards creates more nervousness than moving forwards. In addition, reaction to visual stimuli included minimal tolerance to the dental light and uneasiness to the masked faces of the oral health providers (Kuhaneck & Chisholm, 2012). Furthermore, reaction to smells and tastes included the dental gloves and prophylaxis pastes (Kuhaneck & Chisholm, 2012). Finally, reactions to sounds often produced a fear response to dental equipment such as the polisher, suction, and high-speed handpieces, as well as to general office sounds of intercoms, alarms, and beeps (Kuhaneck & Chisholm, 2012).

The researchers presented recommendations to help diminish sensory stimuli by altering the sensory experience when undergoing oral health care. Also discussed were strategies to help alleviate uncomfortable sensations. The first recommendation was to verbally prepare the patient with ASD by describing what will take place to prevent

startling them and to maintain the assumption that non-verbal patients perhaps understand everything being said to them (Kuhaneck & Chisholm, 2012). Second, with the use of products that have tastes and smells, was to have alternatives to search for patient preferences (Kuhaneck & Chisholm, 2012). The third recommendation related to touch was to use firm deep touch rather than light touch and make as little contact as possible with the face and tongue (Kuhaneck & Chisholm, 2012). Fourth, for visual stimuli, was to avoid direct eye contact, to wear transparent face shields, and to block as much light as possible by providing sunglasses and dimming the overhead lights (Kuhaneck & Chisholm, 2012). Fifth, with movement, was to have the chair fully reclined prior to the patients arrival and finally for auditory, to use white noise or encourage patients to use headphones for their preferred music (Kuhaneck & Chisholm, 2012). On the understanding that oral health care visits can be stressful and challenging, oral healthcare providers should also work with the parent of caregiver to elicit recommendations to make the oral health care visits as smooth as possible.

Similarly, in 2015, researchers in Los Angeles hypothesized that if annoying sensory characteristics of the dental environment were reduced then children with ASD would be less anxious and exhibit decreased uncooperative behaviors (Cermak et al., 2015). The research design for this pilot and feasibility study was an experimental randomized crossover design consisting of two groups, children with ASD and TD children, who received dental care for oral prophylaxis in two different settings, a regular dental environment (RDE) and in a sensory-adapted dental environment (SADE; Cermak et al., 2015). The two study groups were examined and measured by the use of sensors attached to the children's fingers to assess behavioral and physiological distress, pain,

and sensory discomfort (Cermak et al., 2015). Participants between the ages of 6-12 years were chosen from TD families and children with ASD who had experienced at least one oral prophylaxis prior to the last 4-6 months (Cermak et al., 2015). A confirmed ASD diagnosis was necessary for the children with ASD and both groups could not have any comorbidities or siblings with comorbidities (Cermak et al., 2015).

Data analysis was measured in four areas, psychological stress, behavioral stress, pain, and cost of care. Psychological stress was measured with the use of electrodermal activity (Cermak et al., 2015). Various dentist-reported Likert scales were used to measure overt anxiety and distress behaviors, such as the Anxiety and Cooperation Scale, the Frankl Scale, and the Children's Dental Behavior Rating Scale (Cermak et al., 2015). Reports of child experienced pain and sensory discomfort were recorded with Faces Pain Scale-Revised and Dental Sensory Sensitivity Scale (Cermak et al., 2015). Costs were tabulated by time to complete oral prophylaxes, number of staff to safely immobilize the child, and need for pharmacological methods (Cermak et al., 2015).

The SADE modifications were for visual, auditory, and tactile senses (Cermak et al., 2015). In addition, modifications used were blackout curtains, provider headlamps, and slow-moving colored lights on the ceiling within the child's view (Cermak et al., 2015). Finally, calming music played throughout the visit and deep hugging pressure was applied to the child's total body with a butterfly-type wrap and child size x-ray vest (Cermak et al., 2015). The results for this pilot study reported that 44 children participated, 22 children with ASD and 22 TD children all between 6-12 years old (Cermak et al., 2015).

Recruitment and retention was good with only 1 child dropping out from not completing all of the study activities (Cermak et al., 2015). The researchers noted responses to the four interventions studied were physiological measures, behavioral measures, child-response measures, and cost savings (Cermak et al., 2015). First, both groups' (ASD and TD) physiological measures showed a statistically significant group difference or decrease in electrodermal activity when comparing SADE conditions to RDE conditions for all measures (Cermak et al., 2015). Second, response to intervention behavior measures showed a statistically significant group effect for all behavioral measures, with the largest impact noted for environmental distress behaviors shown by the Children's Dental Behavior Rating Scale (Cermak et al., 2015). Behavioral distress comparing SADE versus RDE was 0.29 for the TD group and 0.23 for the children with ASD (Cermak et al., 2015). Third, results for response to intervention for child-reported measures of pain intensity and sensory discomfort in the SADE environment were significantly improved in both groups (Cermak et al., 2015). Researchers noted that only half of the ASD children's group were able to self-report, which produced findings for only a partial sample (Cermak et al., 2015). The final measure for cost savings was equated to time, number of staff, and need for pharmacological methods to complete the treatment (Cermak et al., 2015). Contrary to what was hypothesized, the SADE condition took a mean difference of 5 to 7 minutes longer in both groups; however, fewer staff were needed to restrain the child in the SADE condition and no children utilized pharmacological interventions during the study (Cermak et al., 2015).

Cermak et al. (2015) pointed out the importance of oral health as part of the best possible development for children's physical and mental health. In view of this

importance, the US Department of Health and Human Services listed oral care as the greatest unmet need for children from vulnerable populations (as cited in Cermak et al., 2015). This study provided implications for occupational therapy practice to help decrease health related disparities through the use of sensory processing in stressful health-related situations such as oral prophylaxis in dental offices (Cermak et al., 2015). This pilot study showed that changes in the sensory environment to reduce distractions is key to oral care delivery and worth pursuing on a larger scale study (Cermak et al., 2015).

Limitations of this study were many; first was not studying a population large enough to fully represent a complete range of language and IQ abilities of the children with ASD (Cermak et al., 2015). Because of this level of diminished language ability, future research should aim to include a larger and more diverse group of children with ASD (Cermak et al., 2015). Second was limitations in relation to outcome measures where self-reported measures were not completed from almost half of the children with ASD, blinding was not possible with all study measures, and thoroughness of oral prophylaxis was not considered (Cermak et al., 2015). The third limitation was the effect of introducing a social story about electrode application and the dental cleaning which could have aided in a diminished effect of physiological and behavioral distress (Cermak et al., 2015). The final limitation was the small sample size which precluded the pilot study from measuring the effects of dental anxiety, sensory over-responsivity, and cognitive/language ability in relation to the SADE (Cermak et al., 2015).

Likewise, Nelson et al. (2017) predicted that dental examinations for children with ASD in the context of a dental desensitization program can be successful for those children with a milder presentation of ASD. In this retrospective review of clinical

behavior data, demographic, treatment, and behavior characteristics were studied on 168 non-institutionalized children with ASD. The researchers postulated that children with milder ASD would tolerate a minimal threshold examination (MTE) more readily than children with more severe disability (Nelson et al, 2017). The MTE was characterized as the inspection of the oral cavity with an intraoral mirror while seated in a dental chair (Nelson et al., 2017). It was found that having verbal communication skills, being able to understand language, and being able to achieve self-care skills of dressing were all relevant to the child's ability to comply with MTE (Nelson et al., 2017). Five steps in the desensitization program included a pre-visit questionnaire, behavioral assessment, establishment of an individualized care plan, use of a social story, and recurrent dental visits to accomplish clinical goals (Nelson et al., 2017). This study concluded that desensitization can be practical in cultivating dental skills to children with ASD, that after 1 to 2 desensitization sessions most children with ASD would submit to the dental examination, and that most children tolerated an MTE after 5 visits (Nelson et al., 2017).

To summarize the sensory processing techniques proposed for use with children with ASD receiving oral health care, Kuhaneck and Chisholm (2012) recommended strategies to mitigate obnoxious sensations for children and young adults with ASD while undergoing oral health care visits. Taking a different approach, Cermak et al. (2015) addressed desensitizing the environment to achieve a similar effect, to lessen anxiety experienced and exhibit decreased uncooperative behaviors by the oral health care recipient with ASD. Finally, Nelson et al. (2017) proposed most children with a milder ASD could be desensitized after 1 to 2 sessions and be able to complete an oral

examination. In the next section methods to communicate the delivery of oral health care were presented.

Visual perception and communication. The Picture Exchange Communication System (PECS) is a visually-based communication system used primarily with individuals who have language impairments resulting from an array of disabilities or disorders, especially individuals with ASD (Yoder & Lieberman, 2010). This communication system teaches individuals to communicate by exchanging picture symbols (Lerna et al., 2014). This system of communication has been found to be of particular benefit to individuals with ASD because eye contact is not necessary to successfully teach this technique (Yoder & Lieberman, 2010).

In 2010, Yoder and Lieberman conducted a randomized test of the efficacy of PECS on highly generalized picture exchanges in children with ASD. The researchers studied 36 children between ages 18 and 60 months, 33 with autism and 3 with pervasive developmental disorder. Of the 36 children studied, two interventions were randomly assigned: 19 children were assigned to PECS and 17 children were assigned to Responsive Education and Pragmatic Milieu Training (RMPT). At the end of the training and workshops, the researchers concluded that PECS increased the number of exchanges over that of RMPT. In addition, the researchers explained that PECS facilitated generalized picture exchanges in three ways: between people, with replacement of modes of communication such as gestures and words, and with settings. Finally noted through the research was that PECS promoted peer social communication skills (Yoder & Lieberman, 2010).

During the same year, Flippin et al. (2010) conducted a meta-analysis on the effectiveness of the PECS on communication and speech for children with autism spectrum disorders. The PECS system was fluid in that implementation was simple for both the child with ASD and the presenter, making this system popular for social communication training; for example, eye contact, gestures, and verbal imitation were skills not necessary to be mastered prior to the PECS training (Flippin et al., 2010). PECS was found to be effective in teaching children with ASD to request needs and desires, yet lacked effectiveness in promoting speech in these children (Flippin et al., 2010). Communication outcomes increased following PECS training for single-subject studies with a 95% CI [0.04, 0.67] thus, the presumption could be made. Furthermore, the fact that this study maintained the mean percentage of nonoverlapping data points (PND) of 84.3%, 95% CI [68.4%, 100.1%], suggested that PECS was a reasonably effective intervention for developing communication for young children with ASD (Flippin et al., 2010).

Since this meta-analysis on PECS for children with ASD, researchers have studied how PECS affects the oral health care experience of children with ASD. Although this system has not been widely used in oral health care settings, a few studies have addressed the benefits to patient behavioral compliance by providing a way to make requests known for children with ASD (Flippin et al., 2010; Lerna et al., 2010; Yoder & Lieberman, 2010). With these studies in mind Italian researchers Cagetti et al. (2015) investigated the dental care protocol based on visual supports for children with ASD. The purpose of this study was to present a system of visual supports to offer them the fundamental groundwork to advance through oral examinations and treatments (Cagetti et

al., 2015). Researchers, with the aid of a psychologist, presented a multistage approach for four stages or goals as follows: stage (1) sitting in dental chair to accept an oral examination, stage (2) obtaining a professional oral hygiene session, stage (3) acquiring dental sealants, and stage (4) for those with active caries accepting restorative treatment (Cagetti et al., 2015). Initially, the researchers and psychologists presented prepared visual supports during a one-hour training, repeating this for 8 times twice a week for 4 weeks for each child in the study (Cagetti et al., 2015). Next, parents showed their child the same visual supports while the child underwent the first stage, the oral examination (Cagetti et al., 2015). Once children completed the first stage, additional training commenced at home; parents received additional training to present the visual supports fifteen minutes a day for two weeks to their child with ASD (Cagetti et al., 2015). Each completed stage thereafter was followed by additional parent training and new visual supports for the next stage.

Of the 83 children with ASD in the study, 77 (92.8%) accepted the oral examination and the professional oral hygiene appointment (Cagetti et al., 2015). Furthermore, 70 (84.4%) accepted a preventive procedure for sealants, where 26 (31.3%) did not need treatment, and 7 (8.4%) refused treatment (Cagetti et al., 2015). Finally, 41 (49.4%) children with ASD accepted tooth restoration (Cagetti et al., 2015). For each stage the acceptance rate was compared to the child's verbal abilities, intellectual level, and degree of cooperation during the oral examination stage (Cagetti et al., 2015). A statistically significant association was measured for stage 1 ($p=0.02$), stage 3 ($p=0.04$) and stage 4 ($p=0.01$) for verbal fluency (Cagetti et al., 2015). For intellectual level, just stage 4 ($p=0.04$) was statistically significant (Cagetti et al., 2015). In conclusion,

researchers pointed out that visual elaboration can be supportive for children with ASD at any level of intellectual ability or speech in that visual instructions reduce the amount of words needed and provided a consistent visual message. They also noted that parents' participation with the protocol was essential as they are the most influential resource in promoting change in their child's behavior, and, finally, that oral health care procedures should last the shortest amount of time necessary with the minimal amount of stimulation (Cagetti et al., 2015).

In another PECS study, Wibisono et al. (2016) conducted qualitative research to examine the perception of dental visit pictures in children with autism spectrum disorder and their caretakers. Participants were recruited from a school for children with special needs in Jakarta, Indonesia (Wibisono et al., 2016). Ten autistic children aged 13 to 17, two female parents and two female teachers were presented with pictures of dental clinic personnel and activities and asked open-ended questions (Wibisono et al., 2016). Overall, 32 pictures of dental related activities were presented with questions; each conversation was tape recorded and categorized to extract a theme using Dedoose mixed methods software (Wibisono et al., 2016). The selected codes included reason for visiting, dental clinic exterior, dental visit purpose, waiting room, operation room, staff clinic, dental equipment, and encouragement; sub-codes included environment, behavior, dentist, dental assistant, dental chair, treatment position, dental instrument, dental treatment, equipment sound, gargle, dental bib, mask, glove, lamp, and prize (Wibisono et al., 2016). As a result of the dental visit pictures, 9 of the 10 participants visited a dental clinic and accepted dental treatment (Wibisono et al., 2016). Most pictures were recognized by the participants, and side-by-side pictures with opposite meanings (for

example, with the lamp on or off or the chair up or down) were the easiest to distinguish (Wibisono et al., 2016). The final analogy was that dental visit pictures were useful in that children accepted dental clinic activities better when understandable pictures were presented prior to the actual visit (Wibisono et al., 2016).

Furthermore, in another PECS related study, researchers examined how PECS could facilitate oral health care for individuals with ASD. The intention of this pilot study was to develop patient-professional communication during oral health care and examine the difference of two groups of children with ASD utilizing PECS with or without previous dental experience (Zink et al., 2016). The Brazilian researchers performed a longitudinal study of 26 children, 5 to 19 years old, diagnosed with ASD. The sample was divided into two equal groups. Group (1) had no previous contact with dental care and group (2) had previous dental care experience (Zink et al., 2016). Neither group had been previously exposed to the PECS model. This PECS was designed for dentistry and seven figures were pictured. The figures were in sequence of treatment proposed for the session beginning with “(1) consulting room (“room”), (2) reception room carpet (“ground”), (3) dental chair (“chair”), (4) “dentist,” (5) “mouth,” (6) dental low-speed handpiece (“low”), and (7) dental syringe triple (“triple”)” (Zink et al., 2016, p. 255). Each figure measured approximately 4 inches in diameter with a felt backing and Velcro to affix to a board 16 to 20 inches across as each PECS was acquired (Zink et al., 2016). As each PECS figure was learned and adhered to the board a visualization process took place showing the communication flow. Here the patient learned the steps to the procedure proposed and developed a connection with the oral health professional; one of the primary goals was to create visual contact (Zink et al., 2016). There were three

possible outcomes for each PECS presented to the patient, (1) “acquired:” the skill was learned and the activity was completed; (2) “emerging:” with encouragement the skill was accepted although the patient showed hesitation for the activity; or (3) “nonacquired:” the patient refused the presentation of the PECS and was uninterested (Zink et al., 2016, p. 256). These steps were repeated for each of the seven PECS figures up to three times. As a result, this pilot study found favorable results for the patients with ASD being able to adapt to preventive oral care without the need for physical restraints or general anesthesia (Zink et al., 2016). In addition, the PECS assisted in establishing a relationship between the child with ASD and the oral health care provider (Zink et al., 2016). Furthermore, this study showed that the use of PECS lessened the difficulties patients with restricted communication skills experience during oral health care treatments (Zink et al., 2016). Not necessarily a limitation, the researchers found that children with ASD may need multiple introductions with each PECS before acquiring the skill necessary to become acclimated with the dental environment (Zink et al., 2016). Also, the researchers agreed with previous studies that the parent is key to communication and treatment success for children with ASD (Zink et al., 2016).

Similar to PECS, social stories were a behavioral intervention used for children with ASD by depicting a brief illustration of a particular event or activity, which outlines key information about what to anticipate during that situation (Marion et al., 2016; National Autistic Society, 2018). Brief illustrations provide individuals with ASD an introduction to what can be expected next, how to behave or cope with an infrequent activity, and how to understand sequencing at oral health care visits (National Autistic Society, 2018). In a study investigating dental social stories for children with autism,

researchers explored caregivers' preference regarding dental stories to lay the ground work for children with ASD prior to oral health care visits (Marion et al., 2016). Social stories were provided in printed and digital formats that were selected by caregivers based on the preference of the child with ASD (Marion et al., 2016). At the same time, the researchers acknowledged the difficulty of understanding a child's true preference, which is similar to most people in that preferences are not static (Marion et al., 2016). Conflicting results were recorded where some families acknowledged the social stories assisted successful oral health care visits by reducing the fear of the unknown, while another family pointed out the social story increased anxiety for their child with ASD by furthering the time to obsess about an uncomfortable activity (Marion et al., 2016). Furthermore, the results showed no statistically significant associations between predictive variables and reported usefulness (Marion et al., 2016). The researchers concluded that a child's preference for media format at home was a leading indicator in the format chosen for dental social stories (Marion et al., 2016).

In addition, PECS and social stories are just some of the advancements based on visual perception and communication that have been studied; others incorporate advancements in technology and socio-behavioral interventions. These interventions were utilized for the reduction of dental anxiety and corresponding behavioral deficits in children with ASD (Elmore et al., 2016). In Elmore et al.'s (2016) study, researchers focused on two questions aimed at improving the dental experience for children with ASD; first, what interventions are feasible to reduce dental anxiety and second, which methods are most appropriate for dental hygienists to support children with ASD when receiving oral health care (Elmore et al., 2016). The researchers gathered 38 primary

resources from peer-reviewed journals between the years 2000 and 2014 consisting of intervention studies, case reports, randomized controlled trials, and surveys (Elmore et al., 2016). The selected studies were summarized pertaining to advancements in technology and socio-behavioral interventions into three groups: picture card interventions (PCI), video technology interventions (VTI), and mobile application interventions (MAI) for children with ASD (Elmore et al., 2016).

The PECS was originally designed to help non-verbal children with autism by using cards with a basic picture paired with an explanatory word or phrase to communicate wants or desires (Elmore et al., 2016). This technique has been studied broadly for children with ASD. Another popular behavioral intervention studied was social cue cards paired with a social story which were read before a particular social situation to create understanding rather than to evoke a change in behavior (Elmore et al., 2016). A final PCI studied was functional communication training with picture cards which were primarily used with the intent to disrupt self-injurious behaviors (Elmore et al., 2016). The outcomes of the studies reviewed for PECS suggested that PCI is associated with enhanced spontaneous communication, higher percentages of responses, and increased speech and social communicative behaviors, as well as decreased problem behaviors (Elmore et al., 2016). Next, social stories showed outcomes effective for maintaining targeted social skills (Elmore et al., 2016). Last, functional communication training paired with PECS, study outcomes capitalized on the PECS associated with more desirable, less disruptive, and more appropriately engaged behaviors for children with ASD (Elmore et al., 2016).

Another educational tool for children with ASD was electronic screen media. Research supports children with ASD become engaged with animated visual stimulation (Elmore et al., 2016). VTI developed for children with ASD present desired content in approximately 10 to 26 second video clips. The summary of current literature on video technology interventions depicted outcomes which suggested that stimuli held children's attention, and in one such study audio-visual modeling was effective in facilitating a full dental assessment by increasing compliance (Elmore et al., 2016).

The third intervention studied was MAI. These individually designed applications can be downloaded on smartphones and are readily available for situational use (Elmore et al., 2016). Some of the studies reviewed depicted significant outcomes; however, the heterogeneous nature of children with ASD creates difficulty in providing a broad-spectrum intervention to diminish anxiety and stress as well as improve comfort, cooperation and learning while undergoing oral health care (Elmore et al., 2016).

In summary, techniques such as PECS, social stories, electronic screen media, and MAI are primarily visually based communication systems used with individuals who have language impairments (Elmore et al., 2016; Lerna et al., 2014; Yoder & Lieberman, 2010). When these communication techniques were paired with the delivery of oral health care, Flippin et al. (2010) pointed out that eye contact, gestures, and verbal imitation were competencies not necessary for individuals with ASD to be proficient with this training. Generalized picture exchanges with PECS can be used between people, methods of communication, and settings (Yoder & Lieberman, 2010). PECS was shown in one study to aid children with ASD with an introductory communication foundation to advance through oral examinations and treatments (Cagetti et al., 2015). Yoder and

Lieberman (2010) pointed out that the use of PECS promoted peer social communication skills. Finally, Wibisono et al. (2016) indicated that dental visit pictures were useful in that children accepted dental clinic activities better when understandable pictures were presented prior to the actual visit. Even though visual perception and communication are necessary parts of the provision of oral health care for individuals with ASD, so are behavior guidance and management techniques.

Behavior guidance and management. Behavior guidance and behavior management provided necessary tools and techniques for the oral health care provider when caring for children and young adults with ASD in the dental setting. Traditional or basic behavior guidance and advanced behavior guidance were two types of behavioral management approaches to providing dental care for patients with ASD (Nelson et al., 2015). Although not always effective for patients with ASD, traditional behavior guidance techniques were used in the treatment of fear avoidance and for noncompliance with dental routines (Chandrashekhar & Bommangoudar, 2018; Kupzyk & Allen, 2019). The focus of traditional behavior guidance techniques was to develop a positive relationship between the patient and the oral healthcare provider (Chandrashekhar & Bommangoudar, 2018; Nelson et al., 2015). Traditional behavior guidance techniques, such as tell-show-do, voice control, distraction methods, non-verbal communication, and positive reinforcements have had greater success when working with TD children than those with ASD (Chandrashekhar & Bommangoudar, 2018; Gandhi & Klein, 2014; Hermende & Ikkanda, 2011). Furthermore, children with ASD were less apt to respond to techniques for relationship building than are TD children (Nelson et al., 2015).

Non-traditional approaches to behavior guidance, such as book-based visual pedagogy, social stories, video modeling, desensitization, and nitrous oxide use have had greater effectiveness for individuals with ASD than traditional methods alone (Delli et al., 2013; Gandhi & Klein, 2014). Commonly used for children and young adults with ASD having severe disabilities have been advanced behavior guidance techniques, such as protective stabilization, sedation, and GA (Delli et al., 2013; Hermande & Ikkanda, 2011; Nelson et al., 2015). Loo et al. (2009) pointed out that individuals with severe ASD as well as younger patients had a significantly higher percentage of uncooperative behavior during dental treatment than unaffected patients.

To summarize behavior guidance and management, when oral health care treatments were expected and predictable, patients with ASD were better prepared to tolerate the procedure at hand (Nelson et al., 2015). Gandhi and Klein (2014) described that a comprehensive family centered approach had cultivated collective trust when assessing the child's challenging behaviors and related comorbidities. Furthermore, there is no one treatment strategy that was applied to all patients with ASD; patients with ASD were heterogeneous and the treatment needs to be adapted specifically to each individual (Limeres-Posse et al., 2014). Likewise, Chandrashekhar and Bommangoudar (2018) recommended patient management was influenced by instinct and creativity rather than exact reasoning. Preplanning visits in advance set the stage for smooth appointments by anticipating possible impediments to oral health care delivery (Nelson et al., 2015). Finally, dental management of children with ASD was individualized based on an in-depth understanding of their specific autistic behavioral characteristics (Delli et al., 2013). Ultimately, techniques employed by the oral health care provider are only some

pieces of the treatment puzzle when providing oral health care for individuals with ASD. At the same time, the parents' and children's perspectives on receiving oral health care are the final puzzle pieces needed.

Parents' and Children's Experiences Receiving Oral Health Care

In a study designed to gain an understanding of parents' perspectives on the oral healthcare experiences of their children with ASD and to discover how to better their care, 20 parent participants with interest in their children's oral health care, 8 fathers and 12 mothers, were recruited from a parent support group at Seattle Children's Autism Center (SCAS; Lewis et al., 2015). The participants' children with ASD ranged from 3 to 17 years (4 girls/16 boys) with moderate to severe loss of reasoning skills and/or developmental challenges (Lewis et al., 2015). Data were collected from four focus group sessions (Lewis et al., 2015). Focus group discussions were directed to the following topics: 1) their child with ASD; 2) their experiences of oral care at home and the difficulties encountered, and what helped facilitate oral care; 3) their professional dental care visits, difficulties encountered, and what helped to facilitate these encounters; 4) the ideal dental visit and what these parents wanted the dental providers to know about providing oral care for their child (Lewis et al., 2015). Focus group discussion lasted an hour each and continued until saturation of information was reached (Lewis et al., 2015). The researchers used a grounded theory approach, removed all personal identifiers, and read and coded the forum transcripts independently, in order to identify themes (Lewis et al., 2015).

Findings of this study revealed three main themes. First, there was no one set way children with ASD responded to oral health care and there was irregularity between what

worked to facilitate or hinder care for these children (Lewis et al., 2015). Some children were orally averse which created a barrier to brushing their teeth, where other children were not at all orally averse and tolerated a battery-powered tooth brush (Lewis et al., 2015). Facilitating care for some came from a set routine, time of day, and social stories and these same techniques could prove to be a complete hindrance to care for other children (Lewis et al., 2015).

Second, there was a desire on the part of parents to have comprehensive oral health care for their children with ASD (Lewis et al., 2015). Parents expressed frustration that x-rays could not be taken because of the child's noncompliance and during some visits the only accomplishment was a fluoride treatment (Lewis et al., 2015). Another common thread was wanting anesthesia or sedation to complete more treatment without trauma or pain to their child (Lewis et al., 2015). In addition, another parent wanted to maintain parent-child trust and not be the one who restrained the child (Lewis et al., 2015).

Third, parents wanted tailored oral health care for each child with guidance from parents regarding their child's particular needs (Lewis et al., 2015). The overall consensus from parents was that they know their child the best and would have the most valuable input to share (Lewis et al., 2015). Parents wanted to provide strategies on caring for their child in advance of the dental visit, yet many felt that no one asked them for their perspective of their child's needs and preferences (Lewis et al., 2015).

This qualitative study examined how knowledge of oral health care can be advanced for children with ASD; the researchers concluded that they captured the reality that families understand their children with ASD best (Lewis et al., 2015). From the

parent's perspective, there is no comparison of TD children to those with ASD (Lewis et al., 2015). Techniques which could help one child with ASD could potentially aggravate another child with ASD (Lewis et al., 2015). In addition, using tell-show-do could potentially have the opposite of the intended affect and increase stress by making the experience longer than needed (Lewis et al., 2015). Wearing a compression garment, such as a papoose, could provide comfort for one child with ASD and complete agitation for another child with ASD (Lewis et al., 2015). Parents in the focus group had the general consensus that a pre-treatment questionnaire should be used to outline individual attributes of the patient with ASD to better create an individualized oral care plan (Lewis et al., 2015). Researchers agreed that the parents are the most important resource of information about their child (Lewis et al., 2015).

In a similar study, Stein Duker et al. (2017) developed a qualitative exploratory study examining parents' perception of their children with ASD experience of dental care difficulties and barriers for their children in the dental office setting. In this qualitative study, surveys questioning challenges to oral care were completed by parents of children with ASD ages 2-18 (Stein Duker et al., 2017). The survey questions completed by parents were screening questions which addressed challenges to oral care, focusing on access to care, sensory processing, and behavioral difficulties (Stein Duker et al., 2017). Participants consisted of 13 parent focus group members who had at least one ADS child between the ages of 5 and 18, who spoke English, and who were amenable to participating in a discussion group (Stein Duker et al., 2017). Of the 13 parents selected only nine participated (Stein Duker et al., 2017). Two 3-hr focus groups of parents responding to each other's general experiences were chosen over individual interviews

(Stein Duker et al., 2017). Data were collected through focus group discussions which took place between April 2011 and 2013 (Stein Duker et al., 2017). Groups were comprised of four to five members allowing for ease of participation and were prompted to speak freely to expand on pertinent topics (Stein Duker et al., 2017). The focus groups were semi-structured with specific questions and were led by skilled individuals knowledgeable in qualitative research (Stein Duker et al., 2017).

The results of the focus group discussions concluded with four themes: barriers to care, sensory sensitivities, restraints used during care, and pharmacological interventions used during care (Stein Duker et al., 2017). The researchers pointed out these qualitative findings (four themes) are at the forefront of acknowledging challenges parents confront related to dental visits for their children who have ASD (Stein Duker et al., 2017). As confirmed by earlier studies, barriers to professional oral care are related to the difficulty in finding a dentist with the skills, the training, and the willingness to treat these children (Stein Duker et al., 2017). The focal point of this study centered on how these challenges are experienced by the parent or caregiver; the barriers they explore include dentists' rejection of children with ASD; dentists' misrepresentation of their being knowledgeable and versed in treating children with ASD; a lack of referrals from healthcare professionals to dentists well suited in treating children with ASD; and the cost of specialty dental care (Stein Duker et al., 2017).

However, uncooperative behavior of the child with ASD during the dental appointment was not addressed by the parents (Stein Duker et al., 2017). A notable finding in this study was that parents perceived protective stabilization as more acceptable when they administered it themselves as opposed to the dentist and/or staff

members (Stein Duker et al., 2017). Furthermore, clear communication between the dentist, the parent, and the patient was paramount to reducing parent anxiety, which is inadvertently transferred to the child's anxiety, when behavior guidance options are chosen and utilized (Stein Duker et al., 2017). Conflicting experiences were reported by parents when describing protective stabilization techniques (Stein Duker et al., 2017). Limitations to this study were participant inclusion was based completely on parent-report without standardized diagnostic tools to assess the child's ASD diagnosis, the focus group was conducted in a Southern California area which may not be representative of all areas, and only parents of males were in the focus group (Stein Duker et al., 2017).

Similarly, in the UK, researchers collected data on dental experiences of parents of children with autism to analyze how they perceive dental care can be improved (Thomas et al, 2018). Methods were developed with the assistance of six parents of children with autism (Thomas et al., 2018). Parents assisted in the development of the protocol, participant recruitment, and design of consent forms and the subject matter of the study information sheets (Thomas et al., 2018). Recruitment utilized purposive and snowball sampling strategy and ended when the interviews by the primary researcher ceased to discover new themes (Thomas et al., 2018). Data collection consisted of 17 one hour face-to-face, semi-structured interviews (Thomas et al., 2018). Information was collected on child's age when diagnosed with autism, dental treatment challenges experienced, and oral care provider strategies to mitigate treatment related challenges; interviews were recorded and transcribed word-for-word (Thomas et al., 2018). Data analysis employed NVivo 11 software to scrutinize interview transcripts to develop themes related to research questions (Thomas et al., 2018).

Results showed 17 participants met the inclusion criteria for the study by living in the UK, speaking English, and being the parent of a child who had an ASD diagnosis, was 4-13 years old, was of either gender, had a coexisting condition such as Down's syndrome, epilepsy, ADHD, or learning disabilities, and had at least one dental visit in the past two years (Thomas et al., 2018). Data analysis revealed four main themes developed through the interview process as being: "1) Degree of flexibility of dental environment and team; 2) Confidence of parents to advocate on behalf of child's individual needs; 3) Continuation of service beyond the dental examination; 4) Clear referral pathway to specialist dental services" (Thomas et al., 2018, p. 229).

The first theme of flexibility in the dental environment revealed that parents agreed the oral health care provider needed to be much slower and more prepared to reduce their child's dental fear (Thomas et al., 2018). In terms of the second theme, confidence of the parent, Thomas et al. (2018) pointed out parents' frustration with the difficulty of a simple task of tooth brushing for their child at home which was explained as easier to do, although it was actually much harder to accomplish. In relation to parent experience, Thomas et al. (2018) expressed how one parent described the difficulty of hiding their personal dental fear and anxiety from their child with ASD. Both the third and fourth themes were parent initiated. The third theme, continuation of service, expressed parent dismay with follow-through to sequent appointments, while the fourth theme expressed parent desire for clear referral pathways to specialist dental services (Thomas et al., 2018). This qualitative study produced rich in-depth views of parent's experience of their child with ASD dental examinations. The conclusions drawn by the researchers from this study are, first, that parents are key experts on their children and

provide the greatest insight to managing treatment success and, second, that oral health provider flexibility is a take-a-way component in managing the patient with ASD (Thomas et al., 2018).

In 2018, Wilson and Peterson conducted a scoping review of medical care experiences of children with autism as understood by their parents. The purpose was to discern how the literature depicted the experiences of children under age 18 with ASD in medical care settings from the perspective of their caregivers (Wilson & Peterson, 2018). The health care industry is currently changing to focus on the patient experience, hence the increase in studies in this realm. The authors brought to light that until recently, medical examination experiences, much like oral health care experiences, of children with ASD and their parent's perspective had been relatively understudied (Wilson & Peterson, 2018).

Wilson and Peterson (2018) used a scoping review which answered broad reaching questions: 1) Do children with ASD and their caregivers experience challenges in medical care settings? 2) Are there any needs unique to these children and families in receiving care in medical settings? The first question was used to show how the experiences may or may not be different for children with ASD than typically developing children since children with ASD have more medical encounters. Communication was named as being beneficial between health care providers (HCP) and parents to make the best of these interactions (Wilson & Peterson, 2018).

The sample of journal articles met the following specifications: children under 18 with ASD, children examined within the context of medical care in either primary care or emergency departments, and reported findings of original research published from 1988 –

2018 (Wilson & Peterson, 2018). Reviewed articles focused on perspectives of patients and families in which only a parent/child report was included, while the sample excluded reports without original findings (Wilson & Peterson, 2018). Also excluded were studies targeting financial aspects of health care, an intervention, and or psychological/behavioral services for these children (Wilson & Peterson, 2018). Data analysis focused on the researchers' study identification and selection process which searched electronic databases in the ninth month of 2016 and the first month of 2018 (Wilson & Peterson, 2018). Records were located in PubMed, CINAHL and PsychInfo with studies primarily from the US with a small number conducted in European countries (Wilson & Peterson, 2018).

Results showed that ASD patients' visits were reported to be twice as long as TD patient or other special care population visits (Wilson & Peterson, 2018). ASD patients also had 1.5 times longer hospital stays – possibly due to challenges families face including problem behavior and communication deficits, overwhelming environments, demanding procedures, difficulties in interactions with HCP, communication difficulties, and lack of shared decision making (Wilson & Peterson, 2018). Parents also reported problems ranged from boredom, stimulation from a different environment, and change from usual routines (Wilson & Peterson, 2018).

Facilitators of positive experiences were grouped in three categories: provider initiated, medical settings, and parent initiated (Wilson & Peterson, 2018). Provider-initiated facilitators included acknowledging parents as experts on their child, having ASD and child-specific knowledge, utilizing preparation and flexibility, slowing down and using patience, explaining steps of examination procedure, providing reinforcement,

writing down instructions, and communicating between staff (Wilson & Peterson, 2018). Medical settings facilitators assented to utilizing developmentally appropriate toys, providing weighted blankets, offering noise canceling headphones, incorporating sunglasses, adjusting for low lighting, controlling staff supervision of child, decreasing wait time, ensuring staff education and training, and developing visual aids and social stories (Wilson & Peterson, 2018).

Finally, parent-initiated facilitators assented to providing reinforcement, providing HCP with child-specific information, being prepared, utilizing social scripts, and breaking examinations or procedures into smaller steps (Wilson & Peterson, 2018). One limitation of this study was the narrowed scope to reflect only general medical care in the US (Wilson & Peterson, 2018). For example, literature analyzing families' perspectives on other types of treatments were not included such as anesthesia and dental care which identified similar challenges (Wilson & Peterson, 2018).

In conclusion, five key themes were highlighted. First, challenging child behaviors were a result of demands placed on the children from environmental factors in medical care settings (Wilson & Peterson, 2018). Also, adverse child behavior interfered with care received (Wilson & Peterson, 2018). Second, HCP influenced either a positive or negative medical care experience (Wilson & Peterson, 2018). Third, positive experiences could be supported by assisting child communication, HCP understanding and flexibility, and parental preparedness (Wilson & Peterson, 2018). Fourth, HCP and parents should access helpful educational resources and practice guides (Wilson & Peterson, 2018). Fifth, additional research was needed (Wilson & Peterson, 2018).

Summary of Chapter 2

In summary, Lewis et al. (2015) concluded parents had the perspective that there was no comparison of TD children to those with ASD and strategies that worked for one child with ASD would not necessarily work for the next child. Stein Duker et al. (2017) pointed out transparent communication was paramount to reducing overall anxiety. Last, parents' and children's experiences receiving oral health care carried a similar thread throughout the studies in that parents are experts on their child with ASD and are a valuable resource to the oral health care provider in learning how to best care for their child (Thomas et al., 2018; Wilson & Peterson, 2018). Although studies of parents' experiences with children with ASD were described above, no original primary research was conducted related to the individual or young adults with ASD and their oral care experiences. This gap in the literature pointed to the need for further study on the experiences of the young adult with ASD. The next chapter highlighted the methods used to conduct this study.

Chapter 3 Methodology

The purpose of this qualitative descriptive study was to understand the oral healthcare experiences of young adults who have ASD. The following chapter described the study's research design, research content, research participants, data collection, limitations, proposed statistical analysis, and validity and trustworthiness.

Research Design

The study utilized a qualitative descriptive research design in which young adults with ASD were studied to understand their experiences of oral health care. This research strategy is applicable when examining phenomena where little theoretical or practical knowledge exists (Sandelowski, 2000). The researcher acted as the fundamental mechanism for data collection and conducted a comprehensive analysis which resulted with an accumulation of richly descriptive data (Merriam & Tisdell, 2016). This study applied in-depth, semi-structured interviews utilizing open-ended questioning.

The research questions that guided the conduct of this study were:

- 1). How would young adults with ASD describe their experiences of oral health care visits?
- 2). What strategies do young adults with ASD like or dislike that oral health care providers use to improve oral health care delivery for young adults with ASD?
- 3). How do young adults with ASD respond to various communication techniques presented by their oral health care provider when seeking oral health care?
- 4). What oral self-care recommendations do young adults with ASD like or dislike?

- 5). What are the challenges that young adults with ASD encounter when seeking oral health care?
- 6). What recommendations do young adults with ASD have to improve their oral health care experiences?

Research Context

Semi-structured interviews were recorded by the primary investigator through an audio-recorded face-to-face interview process. All interviews were audio-recorded and the participants' pseudonyms were consistently used throughout all materials to maintain anonymity.

Research Participants

Sample Description

Research participants, young adults ages (18 to 35), were recruited from Community Connections located in Ketchikan Alaska after approval was granted from the Idaho State University (ISU) Human Subjects Committee (HSC). Community Connections is a non-profit human service organization which serves communities in southeast Alaska. The focus of Community Connections was to provide autonomy for community members needing help with developing daily living independence. These community members are individuals of all ages who have developmental disabilities, who are developmentally delayed or at risk, and who have behavioral health needs. The Lead Service Coordinator for Children's Mental Health at Community Connections was the initial point of contact for pointing out the recruitment flyer to potential participants. A recruitment flyer (Appendix A) describing the study purpose, who was eligible, and what volunteers for the study needed to know was made available to individuals who

received services from Community Connections. The flyer provided interested participants with the researcher's email and telephone contact information.

Inclusion criteria for this study included young adults between the ages of 18 and 35 who were diagnosed with ASD. Participants had an oral healthcare visit within the last two years. ASD diagnosis and oral health care visits were confirmed by the participant or by the parent, caregiver, or legal/medical guardian. In addition, participants were able to communicate verbally, in English, and were willing to participate for an hour of interview questioning. The projected sample size included approximately eight or more participant interviews utilizing the process of saturation to determine the final sample size. Saturation was achieved when no new information was garnered through the interview process (Merriam & Tisdell, 2016). It was possible, however, that this study may not reach saturation given that autism is very individualized experience to each person with autism (APA, 2013; CDC, 2018).

Exclusion criteria eliminated potential participants who were non-verbal, did not speak English, did not had an oral health care visit within the past two years, and lacked an ASD diagnosis. A screening questionnaire (Appendix B) was used to qualify young adults who met the study parameters as well as to collect personal demographic information of each individual participant in the study population.

After the initial screening questionnaires were returned to the principal investigator, additional participants were chosen through purposeful sampling utilizing snowball sampling (Creswell, 2014; Merriam & Tisdell, 2016). Purposeful sampling is used with qualitative research to select participants who will best direct the researcher to understand the research questions (Creswell, 2014). Snowball sampling is a common

form of purposeful sampling where qualified participants once interviewed recommend other individuals to participate (Merriam & Tisdell, 2016). An effort was made to exclude patients of the primary investigator from this study. Incentive for participation in this study to completion was either a US\$40 Wal-Mart or Amazon gift card of the participant's choosing.

Human Subjects Protection

Application to the ISU's HSC for full review was required prior to conducting this research. Informed consent was obtained from the participants or from the parent/guardian for those participants who lacked the capacity to make a truly informed decision for themselves (Appendix C). The screening questionnaire identified participants who sign consent for themselves and those who have a designated signor.

Participants were apprised of the meaning of informed consent in person and had the opportunity to ask questions. As part of the informed consent process participants were advised of their right to privacy. Further explained was that the participant's privacy consists of confidentiality and anonymity, which was maintained throughout the interview process. Anonymity continued for the participants with the management and the storage of data with the use of a pseudonym to keep their name unknown. When signing the informed consent form, participants were briefed that their participation was voluntary, and that they had the right to stop participating at any time. Participants were provided time to consider their participation in this study and ask questions. The primary investigator was available to answer any additional questions posed by potential participants. The primary investigator or a member of the research team conducted the consent process and then collected the informed consent forms.

Data Collection

Instruments

After approval from ISU's HSC, participants were recruited through personal networking through the use of snowball sampling (Merriam & Tisdell, 2016). An interview guide (Appendix D) was used to ask the study participants questions. Initially, the interview questions were pilot-tested and recorded with the first participant who met the inclusion criteria for this study, so that an experienced moderator (one or more of the thesis advisors) could offer recommendations, and verify the participant understood the questions. Interviews lasting approximately 30 to 60 minutes were conducted individually, audio-recorded, and transcribed verbatim with the use of a paid professional transcription service.

Procedure and Protocols

A qualitative case study inquiry research design was used in order to determine patterns or themes regarding the oral health care experiences of young adult who have ASD. Once approval was received from the ISU HSC, flyers explaining the study were dispersed to potential participants with an ASD diagnosis by the Lead Service Coordinator at Community Connections. Potential participants who were given the study flyer were expected to follow-through by calling the primary researcher. The primary researcher took sole responsibility to recruit potential participants who received a flyer from the Lead Service Coordinator at Community Connections. Additional participants were recruited through the use of snowball sampling and screened for the study inclusion criteria by the primary researcher (Merriam & Tisdell, 2016). This process of snowball sampling was effectively used to reach out to additional community peers who potentially

meet the inclusion criteria. These additional participants provided proof of an autism diagnosis through their health care provider or documentation in their Individual Education Program (IEP) at Community Connections. The primary researcher made weekly visits to Community Connections to recruit potential study participants, explain the study participant criteria, and describe the importance of the study purpose. Potential participants not readily available to meet in person were recruited and screened by telephone. Those willing to participate were further screened and assessed in person. Preference was given to participants who had not been patients in the principal investigator's dental practice to reduce the appearance of bias. A letter was sent to the lead service coordinator requesting written permission be granted from Community Connections to recruit participants for this study and stated that Community Connections agreed to participate in this process as well as provide the use of a private meeting space, that is calm and quiet without sensory distractions, for the interviews (Appendix E). A thank you letter was sent to the lead service coordinator at the conclusion of all the interviews (Appendix F).

Informed consent forms were explained to potential participants and/or parent/guardians in person by the primary researcher. Upon agreeing to participate, the participant and/or parent/guardian signed the final page of the informed consent form and had the opportunity to retain copies (AASPRE, 2019; Jerskey, Correia, & Morrow, 2014). Young adults with ASD had the legal capability of informed consent when they had the mental capacity to retain and comprehend information, the ability to understand the information in a personal context, and the ability to weigh information and to communicate effectively the outcome (AASPRE, 2019; Jerskey, Correia, & Morrow,

2014). For the purposes of this study participants were required to have parent or guardian signed consent unless they had documented self-consent granted by court order.

Interview questions were distributed by the primary researcher, in advance of the scheduled interviews. Scheduled interviews were conducted by the principal researcher in person and audio recorded with a Sony ICDPX370 Mono Digital Voice Recorder with built-in USB. Interviews took place in a private meeting room at Community Connections, on the telephone in FaceTime, or in Zoom platform meetings to maintain confidentiality. Recorded interviews were transferred by download to a password protected computer. In addition, the voice recorded files were saved on a SanDisk Ultra 32GB microSDHC UHS-1 Card and stored with the Sony Digital Voice Recorder in a fireproof locked safe. The screening questionnaire and the interviewees' transcripts were kept in separate locked areas.

Participant identities were known only to the primary researcher. Pseudonyms were selected for all participants and personal identifiers were removed to maintain anonymity; pseudonyms were used in interviews and on the transcript. Transcripts were professionally transcribed (Appendix G). A professional transcription service was retained. Merriam and Tisdell (2016) pointed out "verbatim transcription of recorded interviews provides the best data for analysis" (p. 131). The transcription service was tasked to transcribe the audio recordings word-for-word. The primary researcher, the thesis committee members, and the professional transcriptionist had access to the digital audio-recordings. The principal investigator listened to the interview recordings to verify the content of the written transcripts was verbatim.

All materials and audio recordings were sent to ISU, Pocatello campus through the United States Postal Service certified mail with restricted delivery requiring a signature, when the primary researcher's thesis defense was completed. These materials are to be held in the ISU secured storage in a locked cabinet in the Department of Dental Hygiene for 3 years and then destroyed according to university policy

Limitations

This study had a number of limitations. First, the size of the cohort of young adults with ASD whose experiences were examined by researchers was small, even though a small sample size is indicative of qualitative research design (Merriam & Tisdell, 2016). Second, even though saturation was a goal of the qualitative descriptive process, this population of individuals with ASD are distinctive in that no two individuals with ASD are inherently alike; therefore, saturation may be an added limitation (Fusch & Ness, 2015). Third, this study interviewed only verbal young adults with ASD who had received oral health care treatment within two years. Individuals who did not have oral health care treatment within two years (*perhaps because of previous negative experiences?*) were not represented. Also, verbal young adults with ASD could have differing experiences than non-verbal young adults with ASD.

Statistical Analysis

Descriptive analysis was used to characterize the demographics of the sample. Information gathered included age, gender, type of ASD diagnosis (Autism, Asperger's Syndrome, PDD-NOS, & ASD-NOS), and the individual's living arrangements. The data regarding the oral health care experiences of young adults who have ASD, produced from the semi-structured interviews, was analyzed simultaneously with data collection

(Merriam & Tisdell, 2016). After the first interview was completed the transcript was reviewed and compared to the research questions aligned with the purpose of the study and then used to guide the next interview. The authors explained that this review and comparison process was repeated over again with each succeeding interview. Merriam and Tisdell (2016) explained this process of each interview building from the last worked to keep the data manageable for the researcher. Furthermore, by analyzing the data throughout the gathering process Merriam and Tisdell (2016) explained data was “parsimonious and illuminating” (p. 197). Analyzing and managing these data for later use was achieved through open coding. Open coding was a process of assigning a word or phrase to the data for easy of future retrieval (Merriam & Tisdell, 2016). This process of open coding was derived in the early stages of analysis when all data were potentially useful (Merriam & Tisdell, 2016). Data were useful when answering the research questions posed by the study. Next, axial coding was when data from open coding were condensed into comprehensive categories (Merriam & Tisdell, 2016). Each researcher coded the same interview and discussed findings until consensus was reached.

Established Validity and Trustworthiness

Establishing validity and trustworthiness was paramount to ensuring that the data from this study were gathered, analyzed, and reported in an accurate and ethical manner (Creswell, 2014; Merriam & Tisdell, 2016). Creswell (2014) explained that qualitative validity was a strength of qualitative research; validity encompasses terms such as trustworthiness, authenticity, and credibility. Merriam and Tisdell (2016) recommended that the researcher(s) check for accuracy by utilizing several methods to ensure authenticity of these data. Methods or strategies used in qualitative research were

procedures such as triangulating data sources; subscribing to member checking; using rich, thick descriptions; clarifying the bias; discussing contrary information; spending a prolonged time in the field; and using peer debriefing which researchers utilized to exhibit accuracy of their results and demonstrate veracity to their readers (Creswell, 2014).

In this study the primary researcher interviewed multiple participants in an effort to triangulate different data sources and for the purpose of developing meaningful themes. Member checking, also described as respondent validation (Merriam & Tisdell, 2016), was utilized through follow-up interviews of participants to provide an opportunity for their commenting on major findings and themes (Creswell, 2014). The researcher used rich, thick descriptions in an effort to provide the reader with a sense of shared experience of the participants' oral health care experience discovered through this study.

Creswell (2014) explained the use of self-reflection, a core characteristic of qualitative research, was necessary to develop an open and forthright narrative. Furthermore, Mantzoukas (2005) explained that reflection was essential to identify the researcher's bias to eliminate this bias from the study for the purpose of insuring research validity and credibility. This process of reflexivity to identify bias was necessary where bias was understood as inseparable from the researcher (Mantzoukas, 2005). Self-reflection or reflexivity was the process of examining oneself as the researcher and the research relationship (Mantzoukas, 2005). Through reflexivity the principal investigator came to this study with the awareness of conformational bias in that preconceptions and assumptions were preexisting. The researcher had the following bias about parents in

general: that parents lack the patience to wait for their children to respond to another adult's or oral health care provider's questions. Parents tend to answer for their children rather than waiting to hear what their child will say. The personal experience of the principal investigator involved wanting to answer questions for her own child and having difficulty waiting for a slow, although forthcoming, response. As a researcher the principal investigator prepared parents, if present for the interviews, to endeavor to remain silent and allow for their young adult to answer for themselves.

In addition to a preponderance of evidence that supported the categories, another method to promote trustworthiness with the research findings was discussing contrary information by showing data that contradicts the general perspective of the categories (Creswell, 2014; Merriam & Tisdell, 2016). Furthermore, the primary researcher spent a prolonged time in the field to provide an in-depth understanding of the case being studied. A pilot interview was conducted by the researcher with two thesis committee members to practice interview skills and reduce bias in conducting interviews. Finally, thesis committee members conducted a peer examination of the data and provided feedback on the results.

Summary of Chapter 3

This qualitative descriptive study collected data by interviewing young adults diagnosed with ASD regarding their experience with receiving oral health care. Open coding identified any unit of data pertinent to the study and axial coding was used to create common categories (Merriam & Tisdell, 2016). Interviews once transcribed were interpreted by the researcher by recognizing common on categories within the interviews. Findings of the study contributed to the body of knowledge in oral health care practices

and address research priorities outlined by the ADHA NDHRA (2016), the Healthy People 2020 Objectives (2018a), the IOM, and National Research Council of the National Academies (2011). Results and discussion were reported in the form of a manuscript to be submitted for publication in the *Journal of Dental Hygiene*. The remaining sections of the thesis reflect the manuscript specifications outlined in the author guidelines located at https://www.adha.org/resources-docs/7833_JDH_Author_Guidelines.pdf.

References

- Academic Autistic Spectrum Partnership Research and Education. (2019). *Legal and ethical considerations*.
https://autismandhealth.org/?a=pv&p=main&t=pv_con&s=con_con&theme=ltlc&size=small
- American Dental Hygienists' Association. (2016). *National dental hygiene research agenda*.
https://www.adha.org/resources-docs/7111_National_Dental_Hygiene_Research_Agenda.pdf
- American Psychiatric Association. (2018). *DSM – 5 fact sheets. Autism spectrum disorder*.
<https://www.psychiatry.org/psychiatrists/practice/dsm/educational-resources/dsm-5-fact-sheets>
- American Psychological Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books9780890425596>
- Autism Society. (2016). What is autism? <https://www.autism-society.org/what-is/>
- Autism Speaks. (2018a). *Autism facts and figures*. <https://www.autismspeaks.org/autism-facts-and-figures>
- Autism Speaks. (2018b). *What causes autism?* <https://www.autismspeaks.org/what-causes-autism>
- Autism Speaks. (2018c). *What is autism?* <https://www.autismspeaks.org/what-autism>
- Blomqvist, M., Dahllof, G., & Bejerot, S. (2014). Experiences of dental care and dental anxiety in adults with autism spectrum disorder. *Autism Research and Treatment*, (238764) 1-9.
<https://doi.org/10.1155/2014/238764>

- Brickhouse, T. H., Farrington, F. H., Best, A. M., & Ellsworth, C. W. (2009). Barriers to dental care for children in Virginia with autism spectrum disorders. *Journal of Dentistry for Children*, 76(3), 188-193. <https://doi.org/10.1007/s40368-013-0075-y>
- Cagetti, M. G., Mastroberardino, S., Campus, G., Olivari, B., Faggioli, R., Lenti, C., & Strohmer, L. (2015). Dental care protocol based on visual supports for children with autism spectrum disorders. *Medicina Oral Patologia Oral Cirugia Bucal*, 20(5), 598-604. <https://doi.org/10.4317/medoral.2424>
- Centers for Disease Control and Prevention. (2018a). *Autism and Developmental Disabilities Monitoring (ADDM) Network*. <https://www.cdc.gov/ncbddd/autism/addm.html>
- Centers for Disease Control and Prevention. (2018b). *Autism spectrum disorder: Data & statistics*. <https://www.cdc.gov/ncbddd/autism/data.html>
- Cermak, S. A., Stein Duker, L. I., Williams, M. E., Lane, C. J., Dawson, M. E., Borreson, A. E., & Polido, J. C. (2015). Feasibility of a sensory-adapted dental environment for children with autism. *American Journal of Occupational Therapy*, 69, 6903220020. <https://doi.org/10.5014/ajot.2015.013714>
- Chandrashekhar, S., & Bommangoudar, J. S. (2018). Management of autistic patients in dental office: A clinical update. *International Journal of Clinical Pediatric Dentistry*, 11(3), 219-227. <https://doi.org/10.5005/jp-journals-10005-1515>
- Chi, D. L., Momany, E. T., Mancl, L. A., Lindgren, S. D., Zinner, S. H., & Steinman, K. J. (2016). Dental homes for children with autism: A longitudinal analysis of Iowa Medicaid's I-Smile Program. *American Journal of Preventive Medicine*, 50(5), 609-615. <https://doi.org/10.1016/j.amepre.2015.08.022>

- Colgate. (2018). *Dental visits: The dentist visit and what to expect*. <https://www.colgate.com/en-us/oral-health/basics/dental-visits/dental-visits-the-dentist-visit-and-what-to-expect>
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Sage
- da Silva, S. N., Gimenez, T., Souza, R. C., Mello-Moura, A. C. V., Raggio, D. P., Morimoto, S., Lara, J. S., Soares, G. C., & Tedesco, T. K. (2017). Oral health status of children and young adults with autism spectrum disorders: Systemic reviews and meta-analysis. *International Journal of Paediatric Dentistry*, 27, 388-398. <https://doi.org/10.1111/ipd.12274>
- Delli, K., Reichart, P. A., Bornstein, M. M., & Livas, C. (2013). Management of children with autism spectrum disorder in the dental setting: Concerns, behavioural approaches and recommendations. *Medicina Oral Patologia Oral y Cirugia Bucal*, 18(6), 862-868. <https://doi.org/10.4317/medoral.19084>
- Du, R. Y., Yiu, C. K. Y., & King, N. M. (2018). Oral health behaviours of preschool children with autism spectrum disorders and their barriers to dental care. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-018-3708-5>
- El Khatib, A. A., El Tekeya, M. M., El Tantawi, M. A., & Omar, T. (2014). Oral health status and behaviours of children with autism spectrum disorder: A case-control study. *International Journal of Paediatric Dentistry*, 24, 314-323. <https://doi.org/10.1111/ipd.12067>
- Elmore, J. L., Bruhn, A. M., & Bobzien, J. L. (2016). Interventions for the reduction of dental anxiety and corresponding behavioral deficits in children with autism spectrum disorder.

- Journal of Dental Hygiene*, 90(2), 111-120.
<https://jdh.adha.org.libpublic3.library.isu.edu/content/90/2/111.full.pdf>
- Flippin, M., Reszka, S., & Watson, L. (2010). Effectiveness of the Picture Exchange Communication System (PECS) on communication and speech for children with autism spectrum disorders: A meta-analysis. *American Journal of Speech-Language Pathology*, 19, 178-195. [https://doi.org/10.1044/1058-0360\(2010/09-0022\)](https://doi.org/10.1044/1058-0360(2010/09-0022))
- Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20(9), 1408-1416. <https://www.nova.edu/ssss/QR/QR20/9/fusch1.pdf>
- Gadbury-Amyot, C. C., Austin, K. S., & Simmer-Beck, M. (2018). A review of the health-related quality of life (OHRQL) model for dental hygiene: Eighteen years later. *International Journal of Dental Hygiene*, 16, 267-278. <https://doi.org/10.1111/idh.12277>
- Gandhi, R. P., & Klein, U. (2014). Autism spectrum disorders: An update on oral health management. *Journal of Evidence-Based Dental Practice*, 14(1), 115-126.
<https://doi.org/10.1016/j.jebdp.2014.03.002>
- Hermende, P., & Ikkanda, Z. (2011). Applied behavior analysis: Behavior management of children with autism spectrum disorders in dental environments. *Journal of the American Dental Association*, 143(3), 281-287. <https://doi.org/10.14219/jada.archive.2011.0167>
- Institute of Medicine and National Research Council. (2011). *Improving access to oral health care for vulnerable and underserved populations*. National Academies Press.
<https://doi.org/10.17226/13116>
- Jacobsen, K. H. (2017). *Introduction to health research methods: A practical guide*, (2nd ed.). Jones & Bartlett Learning.

- Jerskey, B. A., Correia, E. D., & Morrow, E. M. (2014). *Informed consent in adults with autism: Ethical and legal considerations in the United States*.
https://www.researchgate.net/publication/268143694_Informed_Consent_in_Adults_with_Autism_Ethical_and_Legal_Considerations_in_the_United_States
- Kogan, M. D., Vladutiu, C. J., Schieve, L. A., Ghamdour, R. M., Blumberg, S. J., Zablotsky, B., Perrin, J. M., Shattuck, P., Kuhlthau, K. A., Harwood, R. L. & Lu, M. C. (2018). The prevalence of parent-reported autism spectrum disorder among US children. *Pediatrics*, 142(6). <https://doi.org/10.1542/peds.2017-4161>
- Kuhaneck, H. M., & Chisholm, E. C. (2012). Improving dental visits for individuals with autism spectrum disorders through an understanding of sensory processing. *Special Care Dentist*, 32(6), 229-233. <https://doi.org/10.1111/j.1754-4505.2012.00283.x>
- Kupzyk, S., & Allen, K. D. (2019). A review of strategies to increase comfort and compliance with medical/dental routines in persons with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities*, <https://doi.org/10.1007/s10882-018-09656-y>
- Lai, B., Milano, M., Roberts, M. W. & Hooper, S. R. (2012). Unmet dental needs and barriers to dental care among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42, 1294-1303. <https://doi.org/10.1007/s10803-011-1362-2>
- Lerna, A., Esposito, D., Conson, M., & Massagli, A. (2014). Long-term effects of PECS on social-communicative skills of children with autism spectrum disorders: A follow-up study. *International Journal of Language and Communication Disorders*. 49(4), 478-485.
<https://doi.org/10.1111/1460-6984.12079>

- Lewis, C., Vigo, L., Novak, L., & Klein, E. J. (2015). Listening to parents: A qualitative look at the dental and oral care experiences of children with autism spectrum disorder. *Pediatric Dentistry*, 37(7), 98-104. https://www.aapd.org/assets/1/7/s14_E98-E104.pdf
- Limeres-Posse, J., Castaño-Novoa, P., Abeleira-Pazos, M., & Ramos-Barbosa, I. (2014). Behavioural aspects of patients with autism spectrum disorders (ASD) that affect their dental management. *Medicina Oral Patologia Oral y Cirugia Bucal*, 19(5), e467-72. <https://doi.org/10.4317/medoral.19566>
- Loo, C. Y., Graham, R. M., & Hughes, C. V. (2008). The caries experience and behavior of dental patients with autism spectrum disorder. *Journal of the American Dental Association*, 139, 1518-1524. <https://doi.org/10.14219/jada.archive.2008.0078>
- Loo, C. Y., Graham, R. M., & Hughes, C. V. (2009). Behaviour guidance in dental treatment of patients with autism spectrum disorder. *International Journal of Paediatric Dentistry*, 19, 390-398. <https://doi.org/10.1111/j.1365-263X.2009.01011.x>
- Mantzoukas, S. (2005). The inclusion of bias in reflective and reflective research: A necessary prerequisite for securing validity. *Journal of Research in Nursing*, 10(3), 279-295. <https://doi.org/10.1177/174498710501000305>
- Marion, I. W., Nelson, T. M., Sheller, B., McKinney, C. M., & Scott, J. M. (2016). Dental stories for children with autism. *Special Care Dentistry*, 36(4), 181-186. <https://doi.org/10.1111/scd.12167>
- McKinney, C. M., Nelson, T., Scott, J. M., Heaton, L. J., Vaughn, M. G., & Lewis, C. W. (2014). Predictors of unmet dental need in children with autism spectrum disorder: Results from a national sample. *Academic Pediatrics*, 14(6), 624-631. <https://doi.org/10.1016/j.acap.2014.06.023>

- Merriam, S. B. & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation* (4th ed.). Jossey-Bass.
- Merriam-Webster. (2018a). *Challenges*. <https://www.merriam-webster.com/dictionary/challenges>
- Merriam-Webster. (2018b). *Recommendations*. <https://www.merriam-webster.com/dictionary/recommendation>
- Merriam-Webster. (2018c). *Strategy*. <https://www.merriam-webster.com/dictionary/strategy#examples>
- Morales- Chávez, M. C. (2017). Oral health assessment of a group of children with autism disorder. *The Journal of Clinical Pediatric Dentistry*, 41(2), 147-149.
<https://doi.org/10.17796/1053-4628-41.2.147>
- Murshid, E. Z., (2015). Dental knowledge of educators and healthcare providers working with children with autism spectrum disorders. *Saudi Medical Journal*, 36(12), 1477-1485.
<https://doi.org/10.15537/smj.2015.12.12622>
- National Autistic Society. (2018). Social stories and comic strip conversations.
<https://www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx>
- National Institutes of Neurological Disorders and Stroke. (2015). *Autism spectrum disorder fact sheet*. https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Autism-Spectrum-Disorder-Fact-Sheet#3082_1
- Nelson, T., Chim, A., Sheller, B. L., McKinney, C. M., & Scott, J. M. (2017). Predicting successful dental examinations for children with autism spectrum disorder in the context of a dental desensitization program, *Journal of the American Dental Association*, 148(7), 485-492. <https://doi.org/10.1016/j.jada.2017.03.015>

- Nelson, T. M., Sheller, B., Friedman, C. S., & Bernier, R. (2015). Educational and therapeutic behavioral approaches to providing dental care for patients with autism spectrum disorder. *Special Care Dentist*, 35(3), 105-113. <https://doi.org/10.1111/scd.12101>
- Nunn, P. J. (2015). *Oral health care: A whole new language*. <https://www.dentalcare.com/en-us/professional-education/ce-courses/ce21/references>
- Onol, S., & Kırzioğlu, Z. (2018). Evaluation of oral health status and influential factors in children with autism. *Nigerian Journal of Clinical Practice*, 21, 429-35. https://doi.org/10.4103/njcp.njcp_41_17
- Petry, N. M. (2002). A comparison of young, middle-aged, and older adult treatment-seeking pathological gamblers. *The Gerontologist*, 42(1), 92-99. <https://doi.org/10.1093/geront/42.1.92>
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334-40. [https://doi.org/10.1002/1098-240X\(200008\)23:4<334::AID-NUR9>3.0.CO;2-G](https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G)
- Self-care: oral hygiene. (n.d.) *Mosby's Medical Dictionary*, (8th ed.). (2009). <https://medical-dictionary.thefreedictionary.com/self-care%3a+oral+hygiene>
- Stein, L. I., Lane, C. J., Williams, M. E., Dawson, M. E., Polido, J. C., & Cermak, S. A. (2014). Physiological and behavioral stress and anxiety in children with autism spectrum disorders during routine oral care. *BioMed Research International*, 2014, 694876. <https://doi.org/10.1155/2014/694876>
- Stein, L. I., Polido, J. C., & Cermak, S. A. (2013). Oral care and sensory over-responsivity in children with autism spectrum disorder. *Pediatric Dentistry*, 35(3), 230-235.

- Stein, L. I., Polido, J. C., Mailloux, Z., Coleman, G.G., and Cermak, S. A. (2011). Oral care and sensory sensitivities in children with autism spectrum disorders. *Special Care Dentist*, 31(3), 102-110. <https://doi.org/10.1111/j.1754-4505.2011.00187.x>
- Stein Duker, L. I., Henwood, B. F., Bluthenthal, R. N., Juhlin, E., Polido, J. C., & Cermak, S. A. (2017). Parents' perception of dental care challenges in male children with autism spectrum disorder: An initial qualitative exploration. *Research in Autism Spectrum Disorders*, 39, 63-72. <https://doi.org/10.1016/j.rasd.2017.03.002>
- Thomas, N., Blake, S., Morris, C., & Moles, D. (2018). Autism and primary care dentistry: Parents' experiences of taking children with autism or working diagnosis of autism for dental examinations. *International Journal of Paediatric Dentistry*, 28(2), 226-238, <https://doi.org/10.1111/ipd.12345>
- U. S. Department of Health and Human Services. (2018a). *AHS-6.3 Reduce the proportion of persons who are unable to obtain or delay in obtaining necessary dental care*. <https://www.healthypeople.gov/2020/topics-objectives/topic/Access-to-Health-Services/objectives>
- U. S. Department of Health and Human Services. (2018b). *Oral health*. <https://www.healthypeople.gov/2020/topics-objectives/topic/oral-health>
- Wibisono, W. L., Suharini, M., Wiguna, T., Sudiroatmojo, B., Budiardjo, S. B., & Auerkari, E. (2016). Perception of dental visit pictures in children with autism spectrum disorder and their caretakers: A qualitative study. *Journal of International Society of Preventive and Community Dentistry*, 6(4), 359-365. <https://doi.org/10.4103/2231-0762.186791>

- Williams, K. B., Gadbury-Amyot, C. C., Bray, K. K., Manne, D., & Collins, P. (1998). Oral health-related quality of life: A model for dental hygiene. *Journal of Dental Hygiene*, 72(2), 19-26.
- Wilson, S. A. & Peterson, C. C. (2018). Medical care experiences of children with autism and their parents: A scoping review. *Child: Care, Health and Development*, 44(6), 1-11.
<https://doi.org/10.1111/cch.12611>
- World Health Organization. (2019). *Child and adolescent health and development*.
https://www.searo.who.int/entity/child_adolescent/documents/en/
- Yoder, P. J., & Lieberman, R. G. (2010). Brief report: Randomized test of the efficacy of picture exchange communication system on highly generalized picture exchanges in children with ASD. *Journal of Autism and Developmental Disorders*, 40(5), 629-632.
<https://doi.org/10.1007/s10803-009-0897-y>
- Zink, A. G., Diniz, M. B., Rodrigues, M. T. B., & Guare, R. O. G. (2016). Use of a picture exchange communication system for preventive procedures in individuals with autism spectrum disorder. *Special Care Dentist*, 36(5), 254-259.
<https://doi.org/10.1111/scd.12183>
- Zwaigenbaum, L., & Penner, M. (2018). Autism spectrum disorder: Advances in diagnosis and evaluation. *British Medical Journal*, 361:k1674. <https://doi.org/10.1136/bmj.k1674>

Title Page of Manuscript

Understanding Oral Care Experiences of Young Adults with
Autism Spectrum Disorder

This manuscript supports the NDHRA priority area, **Population level:**
Access to care (vulnerable populations)

By

Lauren B. Mirsky, RDH, BS, MS

Clinical Dental Hygienist, Ketchikan Indian Community

Ellen J. Rogo, RDH, PhD

Interim Chair and Professor, Department of Dental Hygiene

Idaho State University

JoAnn R. Gurenlian, RDH, MS, PhD, AFAAOM

Professor and Graduate Program Director, Department of Dental Hygiene

Idaho State University

Correspondence to: Lauren B. Mirsky, RDH, BS, MS

mirslaur@isu.edu, 907-254-1228, PO Box 8233, Ketchikan, AK 99901

The authors have no commercial conflicts of interest to disclose.

Manuscript Abstract

Purpose: The purpose of this study was to understand the oral health care experiences of young adults who have autism spectrum disorder (ASD).

Methods: A qualitative descriptive research design was used to study young adults with ASD. Participants were recruited through purposive and snowball sampling procedures. Semi-structured interviews with open-ended questions were performed and audio-recorded. Pseudonyms were used to protect confidentiality. Interviews were transcribed and data were analyzed simultaneously with data collection. Open coding and axial coding were used to create common categories. Validity was established using investigator triangulation and member checks.

Results: Fifteen individuals participated in the study; ten males and five females. Participants revealed a range of feelings related to their oral care experiences from positive to neutral to negative. Participants identified likes and dislikes to dental hygiene and dental treatment as well as daily self-care practices. Individuals reported that improvements in communication were needed; some did not wish to disclose their ASD diagnosis with their oral care providers. Multiple auditory, visual, and tactile sensory challenges were experienced while waiting in the reception area and during dental and dental hygiene treatment. Recommendations were made to improve oral health care experiences.

Conclusions: This study offered insight into the oral care experiences of young adults with ASD and the challenges they encounter. Additional research is needed to further explore this phenomenon from the perspective of those individuals with ASD who are non-verbal and from the experience of oral health care professionals who are working with young adults with developmental disabilities.

Key Words: Autism spectrum disorder, young adults, qualitative, oral care, barriers to care, perception

Understanding Oral Care Experiences of Young Adults with Autism Spectrum Disorder

Introduction

Over the last 30 to 40 years the upturn in diagnosed autism cases has been rising globally as well as in the US.¹ This increase in occurrence is thought to be a result of better diagnostic practices using broadened diagnostic criteria as well as children being diagnosed at younger ages.¹⁻³ Also considered in this increased prevalence of autism is increased parent awareness; for the majority of cases the cause of autism is linked to genetics and tended to run in families.^{4,5} As the reported incidence of autism increases, individuals with autism will need to find oral health care providers who understand their sensitivities when seeking oral health care.

The 2018 CDC's Autism and Developmental Disabilities Monitoring Network reported the prevalence of autism is 1 in 59 children over the previously reported 1 in 68.² The predominance continues to be 5 times higher in males than females.²

In the fifth edition of its *Diagnostic and Statistical Manual*, the American Psychiatric Association described autism as being four individual diagnoses consisting of autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger's syndrome.⁴ In 2013, these four categories were merged into one diagnostic term of autism spectrum disorder (ASD). ASD is a persistent neurodevelopmental disorder with an early onset beginning in childhood with developmental delays appearing as early as 18 months or even younger with most diagnoses established between year 2 and 3 and lasting throughout life.⁶

Individuals with ASD appear physically normal, yet generally lack socialization abilities.⁶ They often have difficulty with communication including an inability to initiate or continue conversations or to answer questions.⁴ Additionally, individuals with ASD may misunderstand jokes, sarcasm, or teasing.⁶ They generally speak in flat, robot-like, or sing-song speech.⁶ Also characteristic are social issues of avoiding eye-contact and resisting physical contact, extreme reaction to invasion of personal space, and unusual sensory interests or sensitivities.^{4,6}

Impairments with ASD make daily life skills very challenging; however, oral care poses situations with extreme stimuli sensations and individuals with ASD often respond atypically to visual, auditory, tactile, olfactory, or gustatory stimuli.⁷ Studies have shown that individuals with ASD have behaviors that put them at higher risk for oral diseases.⁸⁻¹¹ Behavioral impairments such as difficulty with communication, impaired social interactions, restricted interests and, eating habits, resistance to oral care, and repetitive and stereotyped behaviors can influence an individual's oral health status.⁴ Even though many individuals with ASD have dental visits, many do not receive the level of care essential to maintain good oral health.¹²

Investigations have studied sensory processing issues, communication techniques, and behavioral management for children with ASD when faced with oral health care visits.¹³⁻¹⁵ Glaring fluorescent lights, moving back in the chair, touching in the mouth especially the tongue, and tasting and smelling oral care products are regular sensory characteristics of the oral health care visit triggering children with ASD to react with anxiety and uncooperative behaviors.¹⁵ Consequently, simple behavior guidance techniques such as tell-show-do, distraction, positive reinforcement, and voice control as well as relationship building strategies that are successful with TD individuals may not be successful for individuals with ASD.^{13,16,17} Non-traditional methods of behavior guidance, such as book-based visual pedagogy, social stories, video modeling and desensitization use had greater effectiveness for individuals with ASD than traditional approaches alone.^{16,18}

In one study sensory processing techniques proposed strategies to mitigate obnoxious sensations for children and young adults with ASD while undergoing oral health care visits;¹⁹ whereas, in another study researchers addressed desensitizing the environment to achieve a similar effect, to lessen anxiety experienced and exhibit decreased uncooperative behaviors by the oral health care recipient with ASD.²⁰ Researchers discussed sensory processing for the patient with ASD and had similar recommendations as substantiated in a later study; oral health care providers need to be aware of the many stimuli that occur during oral health care visits and make individualized adaptations for each patient.^{19,20}

Techniques such as verbally preparing the patient with ASD by describing what will take place to prevent startling them, offering alternative products with tastes and smells consistent with patient preferences, using firm deep touch rather than light touch and making as little contact as possible with the face and tongue, avoiding direct eye contact, wearing transparent face shields, and blocking as much light as possible by providing sunglasses and dimming the overhead lights were recommendations to diminish sensory stimuli when undergoing oral health care.¹⁹ Parents' experiences of their children receiving oral health care carried a similar thread throughout the studies in that parents are experts on their child with ASD and are a valuable resource to the oral health care provider in learning how to best care for their child.^{21,22}

Research to date has largely been conducted from the oral health care providers' and parents' perspective. No original primary research has been conducted related to young adults with ASD and their oral care experiences. This gap in the literature confirmed the need for further study on the experiences of the young adult with ASD. Therefore, the purpose of this qualitative study was to understand the oral health care experiences of young adults who have ASD in the oral health care setting.

Methods

This study utilized a qualitative descriptive approach to facilitate an in-depth exploration of ASD individuals related to their oral health care experiences. This research design is appropriate when exploring phenomena where little theoretical or practical knowledge exists.²³ The study underwent full Institutional Review Board approval from the University's Human Subjects Committee and received approval (IRB-FY2020-117).

Purposive sampling is often utilized as the sampling procedure for a descriptive qualitative study.²³ Participants were initially recruited through personal networking by the principal investigator (PI) posting a brochure at a non-profit human service organization which serves communities with special needs in southeast Alaska. Furthermore, the snowball sampling method was used to gain referrals of other individuals with ASD who could be recruited for the study.^{24, 25}

Inclusion criteria consisted of young adults diagnosed with ASD between the ages of 18 and 35, who were able to communicate verbally, in English, who were willing to participate for up to an hour of interview questioning, and who had an oral healthcare visit within the last two years. Exclusion criteria eliminated potential participants who were outside the chosen age range, non-verbal, did not speak English, did not have an oral health care visit within the past two years, and lacked an ASD diagnosis. A screening questionnaire was completed to verify that inclusion criteria were met. The questionnaire included demographic information, living arrangements, type of ASD diagnosis, who signs the consent, date of last oral health care visit, and preferred pseudonym. Informed consent forms were explained to potential participants and/or parent/guardians by the PI.

Six research questions directed the development of the interview guide. These research questions focused on experiences related to oral health care visits; likes/dislikes oral health care providers use to improve oral health care delivery; communication techniques provided by oral health care providers; oral self-care recommendations those with ASD like/dislike; challenges individuals with ASD encounter when seeking oral health care; and, recommendations to improve their oral health care experiences. A series of in-depth, semi-structured interviews utilizing open-ended questioning were conducted by the PI to gain richly descriptive data.^{25, 26} Interviews were conducted either in a private room, by telephone, or in Zoom to maintain anonymity and minimize sensory distractions. Initially, the interview questions were pilot-tested and the co-investigators verified this participant understood the study questions. Preference was given to participants who had not been patients in the PI's dental practice. Interview questions were distributed in advance of the scheduled interviews. Interviews were audio recorded with a Sony ICDPX370 Mono Digital Voice Recorder with a built-in USB.

Participant pseudonyms were utilized during the interviews and on the transcript to protect confidentiality and ensure anonymity. Each interview was transcribed directly following the session and the PI listened to the audio-recording to verify the transcriptions were accurate.

Data regarding the oral health care experiences of young adults who have ASD were analyzed simultaneously with data collection.²⁵ After the first interview was completed the

transcript was reviewed and compared to the research questions to ensure the data were aligned with the purpose of the study, and then used to guide the next interview. Open coding identified any unit of data pertinent to the study and axial coding was used to create common categories.²⁵ Each researcher coded the same interview and discussed findings until consensus was reached.

Validity was established through investigator triangulation with two or more investigators individually evaluating data separately and finding comparable results.²⁵ Respondent validation occurred in which a summary of the transcript was offered to each interviewee for review as part of the peer debriefing process to aid in accuracy and validity of the qualitative data.²⁵ Lastly, member checks occurred by participants who evaluated the preliminary findings and verified the accuracy of the research members' interpretation of the data. Eleven out of 15 participants had confirming responses to support the data analysis.

Results

A total of 15 individuals participated in this study; 10 (60%) were male and five (40%) were female. Ages of the participants ranged from 18 to 35; the average age of the interviewees was 25. Participants resided in eight states from the northwest region of the United States. Twelve (80%) lived at home while three (20%) had independent living arrangements. Autism diagnoses varied across the participant population with 3 (20%) described as having autistic disorder, 3 (20%) described as having pervasive developmental disorder-not otherwise specified (PDD-NOS) and 9 (60%) having Asperger's Syndrome. The following results are presented in relation to the major research questions of the study.

Experiences Related to Oral Care Visits

Participants were asked to describe their experiences related to oral health care visits. A range of responses were provided which showed a continuum of emotions ranging from feelings that were positive to neutral to negative. For instance, Link described being happy stating, "Because I know I can take care of myself. I know when they get done with your teeth, I feel happy." An example of a neutral expression was Evans who reported, "I feel, to be honest, pretty neutral when I go. It's like another thing in my life to do." On the other hand, Rose had a more negative response to her visits stating:

I don't know if they're going to hurt me or if they're not going to hurt me and I have to play it in my head that nothing's going to happen, but there's always that fear that's there.

Additional key quotes representing these emotions are provided in Table I.

Participants were asked to describe how they felt when they encountered a different oral health care provider than the one they were used to seeing. Responses included cautious, apprehensive, inconvenienced, and agreeable. Examples of the quotes related to these perceptions also appear in Table I.

Likes and Dislikes Related to Oral Health Care Delivery

The study participants were asked to identify what they liked or disliked about the strategies that dentists and dental hygienists used to improve oral health care delivery. A variety of responses were provided. For example, Evans stated, "The fact that they treat me like I'm a person and not like a patient," while Bob reported, "Well, if my teeth were clean, I like the compliments that I receive, and the general, amicable atmosphere afterwards." Journey Boy enjoyed "getting a toothbrush," but indicated that "it's just painful and I don't like them picking around in my teeth; if they're poking in my mouth, it hurts." Some participants were uncomfortable getting injections or found other procedures unpleasant, while others were apprehensive of the anticipation of an experience. Sophia explained her concern:

In the moment I'm just thinking, okay when the dentist comes I have no idea what they're going to do. The part I hate the most is not when the dentist comes, it's everything before that, not knowing what's going to happen.

Table II provides supplementary key quotes expanding on likes and dislikes about dental and dental hygiene treatment approaches.

Communication Techniques

Communication considerations was a phenomenon explored with the participants. Examples of positive and negative communication experiences were provided by those interviewed. David stated that "a good hygienist anticipates your needs; if they're paying attention, they're like, hey, you need to sit up or you need to spit into this cup, that's what I consider a good hygienist." Participants encountered negative communication at times. Bob

reported “If I didn’t do a good job cleaning my teeth, [I would be] scolded by the dentist or dental hygienist afterwards.” Additional examples of communication experiences, including non-verbal representations, are provided in Table III.

When discussing communication issues, participants discussed whether or not they disclosed their ASD diagnosis with their oral care providers. The PI pursued further questioning asking participants if they would want their provider to know more about their condition. Table III demonstrates the different perspectives identified. For example, Rose explained:

No, only because I don’t want to be looked at as more different than any other patient that comes through. So, I don’t really disclose anything that could be traumatic or could have that light of myself looked in a different way than anybody else to be in there.

Quinn felt differently, expressing:

I would rather they did know, mostly because they want to be able to get more experience on working with people like me so they’ll know how to treat others who are like me that have autism, PDD-NOS and other symptoms such as that.

Finally, Polar Express stated:

I think it’s something people should be trained to identify. They should treat everybody the same; treat everybody like they might have spectrum. Just have the sense of caring. They shouldn’t treat anybody any different just because you have autism.

Oral Self-Care Recommendations Likes and Dislikes

Participants were asked to describe what oral self-care recommendations they liked or disliked. Responses were equally spread between the two categories. Participants agreed that they liked to brush; however, many pointed out how they forgot to brush a second time during the day as evidenced by David who stated, “I brush my teeth at least once a day, I know I’m supposed to do it twice a day. I try to do it twice a day. I like the feeling of having a clean mouth.” Sophia felt differently about brushing.

I don’t like a toothbrush in my mouth. I don’t like thinking about my mouth. If I draw any attention to it then I’m feeling everything, and it’s really unnerving. It didn’t used to hurt,

but now I have bad oral hygiene because now it does hurt to brush my teeth. But mostly it's just the pressure on my teeth.

Responses to flossing and other self-care procedures were similarly divided as shown in Table IV.

Sensory Challenges during Oral Health Care

Another aspect studied related to the sensory challenges participants experienced during oral health care. These experiences could have occurred while waiting in the reception area or during dental and dental hygiene treatment. Challenges included auditory, visual and tactile sensory experiences. When waiting in the reception area, Elaine explained the difficulty she senses noting,

I've been to a lot of places where many people are, so I would just stay there and wait and try to at least get some bubble space around me so I wouldn't get crushed and try to block out some noise to make sure I can at least get some hearing.

Another example of an auditory sensory challenge was expressed by Karl:

If there's multiple people and they're having two different conversations at once that can be extremely disorienting. When there's just copious amounts of acoustic linguistic stimuli, I actually experience aphasia, where something I don't like perceiving between you and me; it's comprehensive. It's actually as if I have aphasia at that moment with all that stimuli. If I'm trying to actually absorb it all at once, analyze every single detail, but that's impossible.

Tactile sensory challenges were discussed by several participants. Rose indicated that she preferred moderate pressure when being touched stating, "Light [touch] is irritating. I don't like being touched lightly by anybody. So a pressurized touch is a lot better. It's more of a soothing feeling than being lightly touched." Polar Express described how soothing touch was to him especially during a comprehensive head and neck examination. "When they're doing this, [palpating his neck] the more pressure makes me feel like they're actually doing the job right. I like this the most. It's like a massage." Still, Journey Boy felt differently, "I prefer real light

pressure. Because it doesn't hurt as bad.” Additional detailed responses about sensory experiences are listed in Table V.

Recommendations to Improve Oral Health Care Experiences

The last major concept explored with participants concerned recommendations they had to improve their oral health care experiences. Some participants offered recommendations for oral health professionals while others offered ideas for individuals with ASD. Bob suggested that the oral care provider “keep their questions or comments until after they’re done with the procedure so that I could talk to them directly and have a conversation.” Karl was concerned that the provider ensures the patient has “a positive experience the first time. It’ll make coming back easier, and then it actually becomes a routine. If you fail the first time, it might be impossible to actually acquire them as a patient.” Rose offered, “I’ve never been put in situations where other people had to accommodate me. I’ve always had to adapt to my surroundings. I could be more verbal about everything that I have going on.” Table VI offers additional recommendations for oral health care professionals as well to individuals with ASD.

Discussion

This study sought to understand the oral care experiences of young adults with ASD. Providing an opportunity for the voices of these individuals to be heard revealed unique discoveries. First, while some participants felt comfortable reporting their ASD diagnosis to their oral care provider, many indicated they chose not to disclose that information. Having dealt with the stigma of being “different,” they were reluctant to be judged further by someone in health care and preferred to remain silent. They relayed stories of being made fun of or thought of as weird, and did not want that experience in the dental office setting. Huws and Jones²⁷ described how the autism label can be associated with several forms of stigmatizing including enacted stigma or actual prejudice and experiences of discrimination, or felt stigma, in which a person has a perceived fear of prejudice or discrimination whether or not such actions actually occur. Their study of individuals with autism indicated that the boundaries between felt and enacted stigma can become blurred.²⁷

In considering the disclosure of an ASD diagnosis as part of the assessment process, the researchers examined the American Dental Association (ADA) Health History Form, a standard form available for dental practice settings.²⁸ No category is offered for ASD or other developmental disorders. “Mental health disorders” is listed on the form, but individuals with ASD might not consider themselves to have this condition. The only other question on the ADA health history that might be applicable is: “Do you have any disease, condition, or problem not listed above that you think I should know about?” A recommendation would be to add the category “Developmental Disorders” to health history forms and list several examples including ASD. Electronic health history forms can be customized as can paper forms to include contemporary information such as ASD making it easier for patients to provide information that would allow providers to be informed of relevant health information. For those individuals who choose to share their diagnosis, reporting this information on the health history is most appropriate.

Further, many of the participants relayed that their dental and dental hygiene experiences were difficult. While the literature reports behavioral challenges for children with ASD during oral care^{13,14,29} and multiple strategies for managing these challenges are available,^{13,16,17} there is no discussion pertaining to the effects of oral care experiences on young adults with ASD. This qualitative study demonstrated that young adults often suffer from the time they enter the reception area until the end of their dental or dental hygiene appointment. The sounds, sights, smells, and actual treatment can be overwhelming for an individual with ASD. Some individuals feel vulnerable based on the practitioner’s capacity to inflict pain and the loss of control when the practitioner enters their personal space during care. It may be that oral care professionals assume that as a child with ASD matures to a young adult they “get over” or can accommodate the treatment process. It appears that for many of the young adults with ASD, this is not the case. Their experience is more than one of anxiety, it is sensory laden and emotionally charged. If oral care professionals are to provide person-centered care, it is apparent that skills in adaptations for individuals with ASD need to be learned to foster an environment where practitioners adapt to the patient’s needs instead of the patient adapting to the provider.

In addition, communication was a topic many participants expressed was difficult for them. It was made clear to the researchers that some individuals with ASD do not like asking questions; whereas, others did not want too much information, yet they still had the desire to know what was going to happen throughout the visit. The literature supports socio-behavioral interventions for children using picture cards, video technology and mobile applications as a way to reduce dental anxiety and increase communication between the patient and the provider.¹⁴ However, limited literature is available to support the communication needs of the young adult. Another recommendation for dental practitioners would be to provide preparation information in advance of the appointment, throughout the delivery of treatment, and after completion of procedures to anticipate and address needs, respond to questions and concerns, reduce negative emotions and feelings, and improve patient-provider relationships.

This study is not without limitations. Researchers examined the experiences of a small sample of young adults with ASD. The size of the study precludes generalization to all adults with ASD. However, the small sample size was indicative of the purpose of a qualitative research design, which was to yield rich, thick data and an understanding of a unique cohort.²⁵ While this study focused on reaching saturation, this population of individuals with ASD are distinctive in that no two individuals with ASD are inherently alike; therefore, saturation may be an added limitation.³⁰ Further, individuals who did not have oral health care treatment within two years were not represented. These individuals could have had profound oral health care experiences making their stories another element to consider. Lastly, the experiences of non-verbal individuals with ASD could not be included.

Additional research related to young adults and adults with ASD is warranted. Future studies could include considerations related to those individuals who have not sought oral health care for significant periods of time and the factors that would encourage them to participate in the oral health care system. Other studies could examine oral health care professionals' knowledge and experiences working with adults with ASD as well as skill preparation for assessing and treating patients to mitigate their oral health care sensory challenges. While the voice of verbal young adults and adults with ASD can be readily heard, those with ASD who are non-verbal have

yet to be studied. Learning their perspective about oral care experiences may be challenging, yet equally important.

Conclusion

A qualitative descriptive study was performed to investigate the oral health care experiences of young adults who have ASD. Fifteen individuals with ASD participated in audio-recorded, semi-structured interviews which were transcribed and analyzed using open coding and axial coding. Findings revealed that participants experience a range of emotions related to oral health care visits ranging from feelings that were positive to neutral to negative. Multiple auditory, visual and tactile sensory challenges exist for the participants while in the reception area of the dental office and during dental and dental hygiene treatment. Communication between oral health professionals and young adults with ASD needs development and refinement. Further research is indicated to continue to explore the phenomenon of oral health care experiences of individuals with ASD as well as oral health care professionals' knowledge and skill preparation in delivering person-centered care to those with developmental disabilities.

Acknowledgements

The researchers gratefully acknowledge the individuals who volunteered for this study and lent their voices for this important topic.

References

1. Kogan MD, Vladutiu CJ, Schieve LA, Ghamdour RM, Blumberg SJ, Zablotsky B, Perrin JM, Shattuck P, Kuhlthau KA, Harwood RL, Lu MC. The prevalence of parent-reported autism spectrum disorder among US children. *Pediatrics*. 2018 Dec;142(6):e20174161.
2. Centers for Disease Control and Prevention (CDC). *Autism and Developmental Disabilities Monitoring (ADDM) Network* [Internet]. 2018a [cited 2018 Nov 28]. Available from <https://www.cdc.gov/ncbddd/autism/addm.html>
3. Zwaigenbaum L, Penner M. Autism spectrum disorder: advances in diagnosis and evaluation. *BMJ*. 2018 May; 361:k1674.
4. American Psychological Association. *Diagnostic and statistical manual of mental disorders* [Internet]. 5th ed. Washington, DC: Author; 2013 [cited 2018 Nov 26]. Available from <https://dsm.psychiatryonline.org/doi/book/10.1176/appi.books.9780890425596>

5. Autism Speaks. *What is autism?* [Internet]. 2018 [cited 2018 Nov 26]. Available from <https://www.autismspeaks.org/what-autism>
6. Centers for Disease Control and Prevention. *Autism spectrum disorder: signs and symptoms of Autism spectrum disorder* [Internet]. 2018b [cited 2018 Nov 26]. Available from <https://www.cdc.gov/ncbddd/autism/signs.html>
7. Kuhaneck HM, Chisholm EC. Improving dental visits for individuals with autism spectrum disorders through an understanding of sensory processing. *Spec Care Dentist*. 2012 Nov-Dec;32(6):229-33.
8. da Silva SN, Gimenez T, Souza RC, Mello-Moura AC, Raggio DP, Morimoto S, Lara JS, Soares GC, Tedesco TK. Oral health status of children and young adults with autism spectrum disorders: Systemic reviews and meta-analysis. *Int J Paediatr Dent*. 2017 Sept;27:388-98.
9. El Khatib AA, El Tekeya MM, El Tantawi MA, Omar T. Oral health status and behaviours of children with autism spectrum disorder: a case-control study. *Int J Paediatr Dent*. 2014 July; 24:314-23.
10. Onol S, Kirzioğlu Z. Evaluation of oral health status and influential factors in children with autism. *Niger J Clin Pract*. 2018 April;21(4): 429-35.
11. Morales-Chávez MC. Oral health assessment of a group of children with autism disorder. *Int J Clin Pediatr Dent*. 2017 Mar;41(2):147-49.
12. Lai B, Milano M, Roberts MW, Hooper SR. Unmet dental needs and barriers to dental care among children with autism spectrum disorders. *J Autism Dev Disord*. 2012 Jul;42(7):1294-303.
13. Chandrashekhar S, Bommangoudar JS. Management of autistic patients in dental office: a clinical update. *Int J Clin Pediatr Dent*. 2018 May-Jun; 11(3): 219-27.
14. Elmore JL, Bruhn AM, Bobzien JL. Interventions for the reduction of dental anxiety and corresponding behavioral deficits in children with autism spectrum disorder. *JDH*. 2016 April; 90(2):111-20. Available from <http://jdh.adha.org.libpublic3.library.isu.edu/content/90/2/111.full.pdf>

15. Stein LI, Polido JC, Cermak SA. Oral care and sensory over-responsivity in children with autism spectrum disorder. *Pediatr Dent*. 2013 May-Jun; 35(3): 230-35.
16. Gandhi RP, Klein U. Autism spectrum disorders: an update on oral health management. *J Evid Based Dent Pract*. 2014 Jun;14Suppl:115-26.
17. Hermende P, Ikkanda Z. Applied behavior analysis: Behavior management of children with autism spectrum disorders in dental environments. *J Am Dent Assoc*. 2011 Mar;143(3):281-87.
18. Delli K, Reichart PA., Bornstein MM, Livas C. Management of children with autism spectrum disorder in the dental setting: concerns, behavioural approaches and recommendations. *Med Oral Patol Oral Cir Bucal*. 2013 Nov;18(6):862-8.
19. Kuhaneck HM, Chisholm EC. Improving dental visits for individuals with autism spectrum disorders through an understanding of sensory processing. *Spec Care Dentist*. 2012 Nov-Dec; 32(6):229-33.
20. Cermak SA, Stein Duker LI, Williams ME, Lane CJ, Dawson ME, Borreson AE, Polido JC. Feasibility of a sensory-adapted dental environment for children with autism. *Am J Occup Ther*. 2015 May-Jun;69(3):6903220020p1-6903220020p10.
21. Thomas N, Blake S, Morris C, Moles D. Autism and primary care dentistry: parents' experiences of taking children with autism or working diagnosis of autism for dental examinations. *Int J Paediatr Dent*. 2018 Mar;28(2):226-38.
22. Wilson SA. Peterson CC. Medical care experiences of children with autism and their parents: a scoping review. *Child Care Health and Dev*. 2018 Nov;44(6):807-17.
23. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*. 2000 Aug;23(4):334-40.
24. Creswell JW. *Research design: qualitative, quantitative, and mixed methods approaches (4th ed.)*. Los Angeles, CA: Sage; 2014. p. 239.
25. Merriam SB, Tisdell EJ. *Qualitative research: a guide to design and implementation (4th ed.)*. San Francisco, CA: Jossey-Bass; 2016. p. 195-252.

26. Jacobsen KH. *Introduction to health research methods: a practical guide, (2nd ed.)*. Burlington, MA: Jones & Bartlett Learning; 2017. p. 89.
27. Huws JC, Jones RS. Diagnosis, disclosure, and having autism: an interpretative phenomenological analysis of the perceptions of young people with autism. *J Intel Dev Disabil*, 2008 June; 33(2):99-107.
28. American Dental Association. ADA health history form [Internet]. 2012 [cited 2020 Jun 11]. Available from <https://dentalassociates.org/wp-content/uploads/2019/01/ADA-Health-History-Form-Fillable.pdf>
29. Kupzyk S, Allen KD. A review of strategies to increase comfort and compliance with medical/dental routines in persons with intellectual and developmental disabilities. *J Dev Phys Disabil*, 2019 Jan; 31:231-49.
30. Fusch PI, Ness LR. Are we there yet? data saturation in qualitative research. *The Qualitative Report*, 2015 Sept; 20(9):1408-1416.

Table I: Emotional Experiences Related to Oral Health Care Visits

Positive emotions or feelings
<p>"I feel happy that I'm there. You're accomplishing something that often I procrastinated about." (Karl)</p> <p>"I'm pretty happy when I visit there. There's a slight bit of nervousness, but it's nothing to make me panic or anything like that. I'm generally calm. I'm still pretty happy when I visit the hygienist, but the only difference is that there's zero nervousness when it comes to dental hygienists. That's way more relaxed. I was a weird kid. I loved the dentist. I'm generally very calm, very happy going." (Kevin)</p>
Neutral emotions or feelings
<p>"I feel all right. I just feel like it's what has to be done. They're just checking me out, not doing anything bad. And so I just follow it. Because I can't do this by myself. I'm sure my teeth are okay but there's always professionals doing it, making sure I don't get cavities and they point out what I may need some help with." (Elaine)</p>
Negative emotions or feelings
<p>"I'm usually really scared and then that turns into anger. I get mad after being in the situation for a little while, but at first I'm just scared. It's a situation where I've had a lot of negative experiences in the past, and I don't really have a lot of trust for dentists because there's really poor communication there, even when I try to make it clear what my needs are. Then if that's just reinforced then I get angry when I don't feel like I have any control in the situation." (Sophia)</p> <p>"I want to say really scared, but I know it's something that has to be done at least twice a year, once every six months. I would say more inconvenienced than any of those, because it's the only time I figured I tilted the world but I know it's something that needs to be done. I won't feel happy or sad or scared because I know it's just something you got to do twice every year, but I know it's a necessary thing." (David)</p>
Feelings towards a different oral health care provider
<p>"It probably wouldn't be as good of an experience, but I would still be calm. I know that they wouldn't have their job if they weren't qualified. I mean they go through safety training." (Ethan)</p> <p>"I have the utmost confidence in that person. Usually when I go, and it's with a different dental hygienist, as long as they go to school and they know what they're doing, I'm fully fine with it." (David)</p> <p>"It's easier for me especially getting a new person the second time. Once I know them after the first time I know what to expect. The second time is easier than the first time. It's less anxiety for me. The one thing I don't like is when they keep switching people on me. I like to keep the same person." (Polar Express)</p> <p>"That's hard, because even if they're from the same office, if I haven't had them before, any time there's a new person coming into the little enclave that I haven't seen before, I haven't met before, it shakes the whole thing up. Then I'm just spending all my time trying to stop the fight or flight." (Sophia)</p>

Table II: Treatments that Oral Health Care Providers Use Participants Liked or Disliked

Dental hygiene treatment	
Liked	Disliked
<p>"The clean feeling I have when I leave. It's kind of like getting a new mouth kind of clean. So I like that a lot." (Rose)</p> <p>"The thing I like the most is that once it's done your teeth are clean and you know what you're supposed to do to improve if you've been lacking in a certain area. Also, the people there are always nice. They give you a bag of stuff. I remember one time I got this tongue scrubber thing that you put on your tongue and it removed debris from your tongue." (Ethan)</p> <p>"I think what I like most is when they put the fluoride treatment on my teeth, and you have to wear those dentures." (Bob)</p> <p>"For some odd reason I kind of like the X rays. I kind of like working on those. I know how to stay comfortable in those kinds of situations. I don't know why that is, but I do." (Quinn)</p>	<p>"The dental hygienist... I believe I was 10. They took one of the tools underneath my gums and instead of removing it the correct way, they pulled it out and it scarred underneath my gum." (Rose)</p> <p>"Those scrapers, those small metal hooks that scrape the teeth for any plaque. It kind of gives me goosebumps, if it gets to a bad area almost close to my gums, so that's why I have to use my tongue to make sure it doesn't get there. I don't think I could say I dislike it. I just don't want a scraper hurting me." (Elaine)</p> <p>"Sometimes the fluoride varnish that they put on after they clean my teeth tastes nasty. But to prep for that, I usually bring an empty water bottle to collect my spit so that I don't swallow that excess." (Quinn)</p> <p>"I do not like the probing when they go between your teeth and your gums like that." (Polar Express)</p>
Dental treatment	
Liked	Disliked
<p>"I think what I like the most is that I can go in, be in and out. That's what I'm trying to say, is I like the speed of how quickly things get done. Complete care." (Kevin)</p> <p>"My dentist that I go to is really kind. He really knows how to take care of me and make me feel comfortable. He does give me support and encouragement to keep up the good work on my brushing. I like him. I just like his smile. He has a pretty jovial attitude. He's very kind, very friendly and the people that work with him are very nice as well." (Quinn)</p> <p>"I get the very best care. That's something that I like because when I go they take my blood pressure. They do a lot more than the doctor's office so it makes me feel like they are doing a wellness check. I feel like I'm in a hospital setting when I go to the college program, because you know that everything is good with you. I like the service too. It feels like they're pampering you because they're taking care of you." (Polar Express)</p>	<p>"Nothing. It's just painful. I don't like it. I just don't like people working in my mouth." (Journey Boy)</p> <p>"I don't like the shots. And the weird sounds of the instruments they use. I don't like that at all." (Rose)</p> <p>"The shots. Keeping my mouth open for a long time. Mostly that. Shots and anything involving needles. I don't like the needles." (Ray)</p> <p>"Sometimes they don't tell me the difference of what they use to ... the gas thing or the shot thing. They don't tell me which is which sometimes. The last time I went, I got a shot through the arm. I don't know what it was, but all I could remember was I just shook nonstop. So I don't know if it was a reaction or anything like that or if it was nerves. I honestly do not know." (Kevin)</p> <p>"They don't call the day before and remind me of the appointments, that's what I don't like. That's one thing that would help me if they could do that. If they'd call me the night before, it reminds me, it would help me be on time." (Polar Express)</p>

<p>"I can name another thing that I like about the dentist, which is that it's close to home. And it's a very small dentist, which I'm all about small communities. The bigger it is, usually the more overwhelmed I get. But the fact that it's nice and small, it's comforting." (Evans)</p>	<p>"One thing I don't like is how when they're working, you get spit on your face." (Ethan)</p> <p>"When they take molds of my mouth. It feels like there is something foreign in my mouth. It's a really uncomfortable feeling, so it just makes my anxiety goes up when they do those types of things." (Rose)</p>
--	--

Table III: Young Adults with ASD Responses to Communication Practices

Positive communication experiences
<p>"Their attitude, they're very nice, and then they make me relaxed. They say, are you comfortable in your chair? I'm like, all right. And also they're like, Hey, you need to spit, when they filling your mouth up with whatever they are filling it up with. They make me relaxed and comfortable because they know it's kind of a long and thorough process for them to clean your teeth." (David)</p> <p>"I talk to them like they're another person. Usually, I'm not really the best at starting conversations. They meet me, they welcome me. We have a little conversation. Like, how are you doing? Hi, how's your day been? And then we get into the process of cleaning up our teeth. Maybe if I don't feel comfortable with something they're doing within my mouth, I'll make a noise or I'll ask for something, they'll usually provide it. If something feels painful, they'll try and lighten it a bit, so that there's not as much pressure being put on it, so that it doesn't hurt as much." (Evans)</p> <p>"I usually talk with them like I would with someone normally." (Ethan)</p> <p>"I've been increasingly able to [communicate feelings about scaling and sensory things] as I've gotten older and understanding it myself more. As a speech language pathology major the last time I went in to the dentist I was taking an oral anatomy and physiology class, so we did talk about that. I liked that I was able to understand in a more clinical way what it was that was going to happen and express what parts of it were the most challenging, and where things touching was the most challenging, because I have that language to do so." (Sophia)</p>
Negative communication experiences
<p>"It's just once a rapport is established, I think more conversation can occur. But on the initial, I would say alleviating that stress of a new experience is probably the most productive thing someone can do. Experiencing something new with autism is far more stressful than other people. I actually have physiological panic attacks. My heart rate would go up, my blood pressure will increase. I release adrenaline and I actually... if it culminates, I will have a panic attack where I will have to escape or I will become strangely violent potentially, but that it takes a lot of duress for that to culminate." (Karl)</p> <p>"When they ask me questions during the procedure, and I'm unable to answer. Either, before or after the procedure or session, but sometimes they say something to me during it, and you can't exactly answer them when they do that." (Bob)</p> <p>"I don't like when information is too detailed, like when he's trying to explain something to me. I pretty much get the gist of something but I don't like when they go on too far about something because it's like, Okay. I get it." (Quinn)</p>
Positive non-verbal communication
<p>"The best thing that they could do it is make eye contact with me, really start to get to know me, to know what I like and what I don't like." (Quinn)</p> <p>"My current dentist, who I've seen a couple times, I really like. She's the only one I've ever met who takes the conversations that happen behind you and moves them in front of you. She's talking with the dental hygienist, she's getting everything ready within my field of vision, and she's explaining things to me. She's doing the things that I appreciate about my dental hygienist that I think come from having more time, not being as rushed. I really like when she engages me instead of just opening my mouth and sticking stuff in there." (Sophia)</p>
Negative non-verbal communication

"I don't like that I can't read their faces as well because they have a mask on, or they're somewhere where I can't really see their face. That makes it hard, because then I don't feel like I'm getting any non-verbal communication from them really. In the past they've had me do hand signals. Just to tap my stomach if I need to step back for a second. We come up with little codes like that, but that hasn't always worked out in the past. If we come up with the code, and it seems clear, and then in the past I've had dentists not really be onboard with that, even if it's well communicated. I don't know maybe they just forget or this takes all of their attention being in my mouth." (Sophia)

Communicating ASD diagnosis

"No, they don't know that I have an autism spectrum disorder. I don't put it on the health history. I don't want to be treated differently. People treat you weird." (Polar Express)
 "I'd rather they didn't know. Because it's none of their business. It's none of their business." (Journey Boy)

"No. I chalk it up as I'm scared of the dentist. That's about it." (Rose)

"No [they don't know I have an ASD]. I just don't think it would be relevant" (David)

"When I'm working with the hygienist and the dentist, they maintain that extremely professional, tactful, no contact unless necessary, even though they don't know I'm autistic, but that doesn't occur in my experience in other professions." (Karl)

"Yes, the most recent one [dentist] does. I think it probably would've been helpful. Definitely would've been helpful in the past if I had the knowledge myself to be able to communicate that to dentists, or try to find one who had a specialty. But unfortunately, I didn't realize until the past year and a half. But it's been good information to be able to share since then. I wasn't diagnosed until a year and a half ago. I had just joined this clinic. I don't think it's currently in their system, unless it's in there more informally. I don't know. I haven't felt a need to go and formally change that, because I have a relationship with the providers." (Sophia)

"I don't really care if they know or if they don't. I'm pretty sure it's on my health history. It doesn't matter to me either way, but to know, because if I act weird, then they'll know." (Ray)
 "I think they do, but I don't think I've ever really mentioned it. Either my mom mentioned it or I mentioned it. Well at least the hygienist does for sure. I'm not sure about the dentist. I'm very sure I haven't told the dentist. I would like them to know that I have it [ASD], because maybe then it'll be beneficial if they knew." (Kevin)

Table IV: Oral Self-Care Recommendations Young Adults with ASD Like or Dislike

Like
<p>"I have the little tiny toothbrush. It's a round head. Maybe a third of the size of a regular toothbrush head. It lets me do it more one place at a time, and it lets me clean probably better than a regular toothbrush without it becoming too much of a sensory experience as it normally would. Having that little tiny toothbrush has been a lifesaver. It's still hard, and so I don't do it as often as I need to, obviously. But it means I can handle it at all." (Sophia)</p> <p>"I'm bad at it [brushing my teeth] though. I like doing it because that it gets rid of that gritty feeling. I scrape myself with tools. Dental tools. I acquire them myself and I scrape" (Karl)</p> <p>"I do like brushing especially when I get around the gums, it actually feels like I'm massaging them a bit better. It actually feels pretty comfortable. I will be honest and say I don't really brush too much. I brush at least once a day and I don't floss too much. I take my own fingers, after I've washed my hands, of course, and sort of massage my gums so that way I don't really get gingivitis." (Quinn)</p> <p>"I don't like a manual toothbrush. I do this [shows an electric toothbrush]. I just scrub it and brush my tongue too." (Polar Express)</p> <p>"I like doing the floss, because it gets my teeth cleaned. That's the thing I liked the most and that tongue scraper." (Ethan)</p> <p>"I use fluoride rinse and some kind of fluoride toothpaste. I put it on my toothbrush and brush my teeth with that twice a week, or at least I try to." (Bob)</p>
Neutral
<p>"I never liked nor dislike it [daily oral hygiene], I know it's just something that I have to do." (David)</p>
Dislikes
<p>"I don't like how the toothpaste always gets bubbly and fills up my mouth." (Ethan)</p> <p>"Flossing hurts and I don't like doing it." (Rose)</p> <p>"When I floss and I use the same floss picker over and over again after several uses, and sometimes it gets stuck in my teeth and then I have to cut it out." (Bob)</p> <p>"Mouthwash. I do not like [one brand of mouthrinse] because it burns. I like the bubble gum flavored kind." (Polar Express)</p> <p>"I don't like mouthwash. I don't like using it. I don't like the taste of it, well, except cinnamon. Cinnamon that is the only exception. I do not like using mouthwash at all." (Kevin)</p> <p>"I do grind my teeth a lot, so we got a mouth guard. I really wish I could use it, because I wake up with little chips all the time, and it would be great if I could use it. But I couldn't. I couldn't handle the feeling of it in my mouth." (Sophia)</p> <p>"I don't like how you have to do it [brush and floss my teeth] so often. I'm bad at it. Sometimes I'll forget over two days. Then I get really gritty and then I just get upset. I need my teeth smooth" (Karl)</p>

Table V: Sensory Challenges Encountered When Seeking Oral Health Care

Auditory Sensory Challenges
<p>"I don't like it [the waiting room] very much because I don't do well with large groups of people. So if there's more than four or five people, I become nervous of saying the wrong thing or doing something that's not appropriate or having those, I guess you could say ticks that some people wouldn't quite understand what is going on. So the more people, the more obvious things could be noticed. Then if there are only a few people, then it's more likely that they're really not paying attention to what I'm doing or how I'm acting." (Rose)</p> <p>"It's a fearful feeling of is that sound's supposed to be making that sound or what instrument are they really using and how are they really using that and is that something that I could be able to cope with during my visit. I also have what they call is an auditory processing disorder. So I hear everything at the same level of sound. So whether it be down the hall or in the room that I'm in, it sounds the same pitch. There's no drowning any other sounds out." (Rose)</p> <p>"It's both [the sound and the feel of all instruments and equipment]. Equally bad, I think it's hard to separate them but I think it's more the feeling. The sound of scraping is hard. I've tried to wear earplugs in the past, but that made the sound worse because it's in your head. So you can hear. Headphones would make it worse only because then I wouldn't know what is going to happen and what is happening because I wouldn't be able to hear it." (Sophia)</p> <p>"It's the thing that cleans the glue off from the brackets. [a high-speed hand piece with a burr] That is the thing that I hate the most. Right underneath that is the polishing. The vibration and the noise, but the vibration more than the noise." (Polar Express)</p> <p>"Pretty much both [the sound and feel of instruments] because sometimes you'll hear the equipment in the other room and be like, no, I'm glad I'm not that guy. It's going through my head right now, all the noise. It's like nails on a chalkboard. You don't like it, but they're getting all the plaque and gunk out of your teeth. It's not a very pleasant sound and it's not very comfortable, but they got to do what they got to do." (David)</p> <p>"I don't know what the sounds mean, and what's happening. They sound powerful, and scary, and unless somebody is there actively walking me through it and telling me what those sounds are then it gives me a lot of anxiety, and especially when I'm listening to other patients in adjacent rooms. I have to try really hard to tune those people out, and their conversations, and their tools. Kids crying. I have to keep my bubble." (Sophia)</p>
Visual sensory challenges
<p>"One thing I don't like is how the light is always really bright. The light up above your head and you always have to close your eyes that is also when they're working." (Ethan)</p> <p>"The hardest thing is just the sensory experience with the lights" (Sophia)</p>
Tactile sensory challenges
<p>"I would say minimal touching. The important thing is appropriate physical contact. Tactile senses to me are a bit different. They can be skin to skin contact can actually be immediately cognitively compromise it, just because it's more of an intense sensation. I don't get that when it's glove on skin contact. That's the thing. When someone touches me with their hand, that's when I instantly start perceiving what their hand is like, and then I have to break down every part of that tactile experience." (Karl)</p> <p>"With other autistic people, I imagine they might experience this as well. It's just being touched skin to skin can be disconcerting because it interrupts your thought process and you're just trying to get through that experience, but then you're interrupted by that and it can cause senses of panic." (Karl)</p> <p>"Inside my mouth, the inside of my cheeks and my gums, it's like this electric pain. It just makes me want to scream. But I get desensitized to it as it goes along. It's not something that builds.</p>

Some of the things build, the tools that builds but just in general having this brushing inside of my mouth gets better as it goes. Outside it doesn't. Outside doesn't bother me too much but my lips and my gums on the inside of my mouth." (Sophia)

"Pressure is better for me. Touch wise, I'm a sensory seeker, and like things that are uncomfortable. It's kind of a doubled-edged sword though, because when it's stronger its better sensory wise but it also makes me feel restrained, even if they're not doing it in a restraint kind of way it makes me feel like I'm losing control in the situation. But pressure is better overall." (Sophia)

Table VI: Recommendations to Improve Oral Health Care Experiences

Recommendation for oral health care providers
<p>“Just maintain that professional tactfulness when it comes to touch. Initial impressions are really important for people with autism spectrum disorder.” (Karl)</p> <p>“I'd meet the dentist and the hygienist at the same time, briefly, and then have the dentist leave. They'd only be there for a second, but at least be there, we've exchanged words before they come in for the second time so that there's some layer of trust there. Kind of what to expect and they might know more what to expect, because I can be clear about my situation. But then not stay too long, because I am really afraid of dentists and then just talk to the dental hygienist for the rest of it.” (Sophia)</p> <p>“Just never comment on someone's facials expressions or kind of the tone of their voice or the volume of their voice. I don't have the best control over because at times when I'm excited, I actually start talking super loud to the point of where I'm yelling, but I'm not actually yelling in anger. You start actually losing control of your ability to regulate such things when you're under duress. It's counterproductive to actually point that out or mock it.” (Karl)</p> <p>“Well one thing that a lot of dentists should do is be nice. Hire nice people and be patient with whoever they're working with.” (Ethan)</p> <p>“They should just to try to anticipate their patient's needs and try to be fast but also thorough at the same time.” (David)</p> <p>“Probably letting me know the steps as a process going between each step. Now I'm going to do this, and then complete that step and then move on to the next one and let me know what's going on as we go through the process.” (Rose)</p> <p>“Well, for the dental hygienist, I think the best option is to use the fluoride polisher first and then do the scraping.” (Bob)</p> <p>“The smell can be a little bit unusual. So, I would have scents like... more pleasant scents in the office, like a sweet lavender smell; and it would also help to calm someone down, especially if they're a little less comfortable around being in the dentist's office.” (Quinn)</p> <p>“Put tons of numbing cream.” (Journey Boy)</p>
Recommendations for other patients with ASD
<p>“I try to focus on one sensation. I hate the light but sometimes if I just stare into it, and try to have that be the only thing that I'm experiencing, even though it's not comfortable, that'll take my mind off of the other sensations. I also can't brush my teeth beforehand, unfortunately, because it makes me aware of my mouth already. So I'm going in, in a state of being hyper aware of all the sensations in my mouth. It's a lot better if I just go in, and it starts there. I don't brush my teeth beforehand, I floss beforehand, like that day.” (Sophia)</p> <p>“I do deep breathing exercises. Just breathe through my nose, out my mouth. Going to a happy place mindset also helps.” (Kevin)</p> <p>“I have this medicine that I use called Lorazepam, and if anyone else has a prescription for it, I would recommend them taking one before they go to the dentist or the hygienist, if they need it, of course. It calms you down. It's an anti-anxiety medicine. You take it as needed. It's never like on a day to day basis, because it's addictive.” (Bob)</p> <p>“Sit in my car for a while and calm down beforehand. I didn't stay in the waiting room. They just got me from just outside the door, and then I went straight in. I avoid the waiting room as long as I can wait outside, or in a bathroom or something.” (Sophia)</p>

VOLUNTEERS NEEDED

for a study understanding *the oral healthcare experiences of young adults who have an autism spectrum disorder (ASD)*

Who is eligible?



Individuals who...

- Are age 18 to 35 years old
- Have an ASD diagnosis
- Have had an oral healthcare visit within the past 2 years
- Can communicate verbally in English
- Are willing to participate in up to an hour of interview questioning

Study participants who finish the interview process will receive either a \$40 Amazon or Walmart gift card!

This study is being conducted by:

Lauren Mirsky, RDH, BS, MS (c)
(mirslaur@isu.edu, 907-254-1228)

with her thesis advisors, Ellen J. Rogo, RDH, PhD (rogoelle@isu.edu, 208-251-3940) and JoAnn Gurenlian, RDH, MS, PhD (gurejoan@isu.edu, 208-240-1443) in pursuit of her MS degree at Idaho State University. You may contact any one of these individuals with questions or concerns.

What you need to know:

- There are 9 eligibility screening questions
- The interview will take less than 60 minutes to complete
- You will receive the interview questions in advance
- You and the interviewer will meet in a private room (via/Zoom or FaceTime)
- You will receive your choice of either a \$40 Amazon or Walmart gift card when you complete the interview!
- You are a volunteer and can stop the interview at any time
- Your answers and information will be kept confidential among the research team, and your answers will not be connected to you
- There is a small chance of risk which includes a confidentiality breach

Appendix B – Screening Questionnaire

Volunteer - Screening and Demographic questions:

Name: _____

- 1). What was your age at your last birthday? _____
- 2). What is your gender? _____ Male _____ Female _____ Prefer not to say
- 3). What is the primary language you speak? _____
- 4). When was your last oral health care visit? _____
- 5). What pseudonym (a made up name to protect your privacy) would you like selected for this study? _____

Parent/Caregiver - Screening and Demographic questions:

- 6). What is the volunteer's living arrangements? _____ Home _____ Group Home
_____ Independent _____ Supported Living
- 7). Who signs consent for this volunteer? _____ The volunteer signs own consent
_____ parent/caregiver signs consent
_____ legal/medical guardian signs consent
- 8). Does this volunteer have an Autism Spectrum Disorder (ASD) diagnosis?
_____ Yes _____ No
- 9). If yes, what is the diagnosis defined as: _____ Autism _____ Asperger's Syndrome
_____ Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
_____ Childhood Disintegrative Disorder _____ Other

Telephone number: _____

Days and times available for study: _____

Appendix C – Human Subjects Committee Informed Consent Form

You are being asked to participate in a research study conducted by Lauren Mirsky. Lauren works at a dental office. She has gone back to college to learn more about her job as a Dental Hygienist. You have been asked to participate in this research because you are between the ages of 18 and 35 with an Autism Spectrum Disorder diagnosis. Please read all the information before you decide to participate in this study. Feel free to ask Lauren questions about the study. After you read all the information, if you decide you do not want to participate, let Lauren know.

PURPOSE OF THE STUDY

The purpose of this study is to understand how you feel about visiting the dentist's office and how you enjoyed or disliked your visit.

PROCEDURES

Your participation is completely voluntary. Your decision on whether to participate or not will have no impact on your dental care in the clinic where Lauren works or on the services you receive at Community Connections.

To be included in this study you must be between 18 and 35 years old, have an autism diagnosis, have had a dental visit within the past two years, be verbal, speak English and be willing to be interviewed for up to an hour. You cannot be part of this study if you are younger than 18 or older than 35, lack an autism diagnosis, are non-verbal, and do not speak English.

If you agree to participate, you will need to sign a consent form. After you sign the form, return it to Lauren. This document will be filed under a pseudonym (a made up name to protect your privacy) as will all materials relating to your interview.

Lauren will ask you many questions for about an hour. Only you and Lauren will be at the interview. You will be given the interview questions about a week before the interview to look over. You will be asked questions about your visits to the Dentist's office and how you felt about the experience. You will be asked if you like or dislike your visit, why you feel the way you feel and what could make your experience at your dental visit better.

The interview will be recorded and downloaded to a password protected computer and a separate external hard drive which will be kept in a locked cabinet. Only your pseudonym (fake name) will be used in the interview and on the transcript. The only people that will have access to your interview will be Lauren Mirsky, the thesis committee members, and the professional transcriptionist.

Word-for-word transcription of the audio-recording will be completed by a professional transcriptionist. The professional transcriptionist will only know the pseudonyms (fake names) of the participants. The transcriptionist will sign a confidentiality agreement. This means that they will not be allowed to talk about the audio recording of your interview to anyone. Every effort will be taken to keep the audio recordings confidential.

After all of the participants have been interviewed, you will receive a copy of your interview to review. This review will take about 1 hour to read and provide feedback on Lauren's understanding of your experiences while visiting the dentist's office. If there is something that does not sound right to you, please let her know. Your feedback is requested back within 7 days or less.

PRIVACY AND CONFIDENTIALITY

No information about you, or provided by you during the research, will be disclosed to others without your written permission. When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. During the personal interview, the conversation will be recorded and later transcribed using your pseudonym (fake name) as the identifier. All computer files and audio-recordings are maintained in a locked cabinet with access only available by the researcher and the faculty thesis chairpersons. After Lauren presents the results of the interviews, all of the audio-recordings and transcripts will be stored in secured storage at Idaho State University for 3 years and then destroyed according to university policy.

POTENTIAL RISKS

Because of the risk of emails being read by people not related to the study, Lauren will contact you in person regarding your participation with this study. If the interview and other contact with her is creating stress for you, she will stop the interview and all contact regarding this study.

ANTICIPATED BENEFITS TO PARTICIPATION

You have the right to not participate in this research study and withdraw from the study at any time. Participants who qualify for the study and who complete the study to the end will receive their choice of either a Wal-Mart or Amazon \$40 gift card as a token gift for their participation.

ANTICIPATED BENEFITS TO SOCIETY

Information that is gained from this study will add to the scientific information needed for people that work in the dental hygiene field.

PARTICIPATION AND WITHDRAWAL

Your participation in this research is VOLUNTARY. You may choose not to participate at any time.

IDENTIFICATION OF INVESTIGATORS

If you have any questions during the interview, feel free to ask Lauren at any time. In addition, you may contact my thesis advisors at the Department of Dental Hygiene at Idaho State University.

Investigator

Lauren Mirsky, RDH, BS, MS(c)

Phone: 907-254-1228

Email: mirslaur@isu.edu

Major Thesis Advisor

Ellen J. Rogo, RDH, PhD

Idaho State University

Phone: (208)251-3940

Email: rogoelle@isu.edu

Committee Thesis Member

JoAnn Gurenlian, RDH, MS, PhD

Graduate Program Director

Idaho State University

Phone: 208-240-1443

Email: gurejoan@isu.edu

I have read the information provided above. I have been given an opportunity to ask questions, and all of my questions have been answered to my satisfaction. I have been given a copy of the informed consent form. I give my consent for the results of the research to be published or discussed in conferences using my pseudonym (a made up name to protect my privacy), no information will be included that would reveal my identity.

I HAVE REVIEWED THIS CONSENT FORM AND UNDERSTAND AND AGREE TO ITS CONTENTS.

_____ Signature of Research Participant	_____ Date
_____ Signature of Parent, Guardian, or Power-of-Attorney	_____ Date
_____ Describe authority to sign Signature of Investigator	_____ Date

Appendix D – Interview Guide

Interview Questions:

- 1). Can you tell me the difference between the dentist and the dental hygienist?

- 2). How do you feel when you go to the dentist? Do you feel happy, sad, mad, or scared? Can you tell me why you feel this way?

How do you feel when you go to the dental hygienist? Do you feel happy, sad, mad, or scared? Can you tell me why you feel this way?

- 3). What do you like the most about going to see the dentist and the dental hygienist? What don't you like about going to the dentist? What do you like that the dentist does? What do you like that the dental hygienist does?

What do you not like that the dentist does? What do you not like that the dental hygienist does?

- 4). How do you talk or visit with the dentist or hygienist when you visit? If you haven't been able to talk with them the way you like, how would you do it?

- 5). Do you like brushing and flossing your teeth? How else do you like to keep your teeth clean? Is there something that you don't like?

- 6). Was it easy to go see the Dentist? If it was not easy, can you tell me why?

- 7). How would you make your visit to the Dentist's office better?

Appendix E – Request Letter

Lauren Mirsky, RDH, BS, MS(c)
16409 Waterfall Road
Ketchikan, AK 99901
(907) 254-1228
mirslaur@isu.edu

October 4, 2019

Sarah Daly
Lead Service Coordinator Children's Mental Health
Community Connections
721 Stedman Street
Ketchikan, AK 99901

Dear Sarah:

I have finally reached the point in my graduate program at Idaho State University that thesis is my last and final focus. It has been months since I first talked to you about my thesis plan to interview young adults who have an autism spectrum disorder. I have presented my thesis proposal and I am ready to apply to the Human Subjects Committee (HSC) for full review which will be necessary in which to begin my research.

At this time I am writing to you to request written permission to have my recruiting fliers distributed to Community Connections participants once my HSC review is complete and approved. In addition, I would also like to ask if I would be able to meet with willing participants and interview them in a private space at Community Connections. A written response by October 18th outlining Community Connections willingness to participate in the study process by distributing my study flyer and providing a private meeting space will be a necessary step for me to include to the HSC in my application.

I truly appreciate your generous offer to assist in my research participant search by allowing me to distribute a flier and recruiter eligible participants from Community Connections for my qualitative study. I will call you next week. In the meantime, please let me know if you have any suggestions to aid in my eligible participant search, and thank you again for your help.

Sincerely,

Lauren Mirsky, RDH, BS, MS(c)
Major Thesis Advisor
Ellen J. Rogo, RDH, PhD
Idaho State University
Phone: (208)251-3940
Email: rogoelle@isu.edu

Appendix F – Thank You Letter

Lauren Mirsky, RDH, BS, MS(c)
16409 Waterfall Road
Ketchikan, AK 99901

November 30, 2019

Sarah Daly
Lead Service Coordinator Children's Mental Health
Community Connections
721 Stedman Street
Ketchikan, AK 99901

Dear Sarah Daly:

Thank you for your help and support at Community Connections as I worked with young adults with an autism spectrum disorder to fulfill my research studies at Idaho State University. Your participation in introducing me to potential volunteers for my study was an enormous help and your part in this process hasn't gone unnoticed. Furthermore, I am grateful for your assistance in securing a private space in which I could meet with eligible study volunteers.

With sincere thanks,

Lauren Mirsky, RDH, BS, MS(c)

Major Thesis Advisor
Ellen J. Rogo, RDH, PhD
Idaho State University
Phone: (208)251-3940
Email: rogoelle@isu.edu

Appendix G- Confidentiality Agreement for Transcription Service

Security & Privacy at Rev

Customer privacy & security are critical to our business and yours. We handle sensitive information with the care it deserves.

Storage & Transmission

All customer files are encrypted both at rest and in transit. Communications between you and Rev servers are encrypted via industry best-practices (HTTPS and Transport Layer Security 1.2). TLS is also supported for encryption of emails.

Backup & Recovery

Rev backs up data constantly to prevent any loss or corruption. All Rev & customer data is hosted at Tier IV or III+, SSAE-16, PCI DSS, or ISO 27001 compliant facilities in the United States.

Availability & Access

We maintain a redundant infrastructure with 99.9% uptime. All customer data is accessible to staff only to the extent necessary to perform the required work. And just like our customer support, our Security Team is on call 24/7 to respond to security alerts and events.

Rev.com – All Rights Reserved Page 1

Rev Information Security & Privacy Program Overview

Introduction

The following document provides an overview of Rev's Information Security & Privacy program. We advise reviewing this document in its entirety as an overview and seeking any additional details in the appropriate attached documents.

Rev.com's advanced platform is a multi-tenant, multi-user, on-demand service providing unbeatable quality, speed, and value to clients and freelancers alike. Rev.com may be securely accessed 24x7 through any Internet-connected computer with a standard browser, an application program interface (API), or mobile applications.

Objectives

Security is a critical part of our business. With our security & privacy program, we strive to achieve the following goals:

1. Ensure that customer data is encrypted and inaccessible to other customers and the public.
2. Ensure that customer data is accessible to staff only to the extent necessary to perform the required work.
3. Prevent loss or corruption of customer data.

4. Maintain a redundant infrastructure with 99.9% uptime.
5. Provide timely notifications in the unlikely event of a downtime, data corruption or loss.
6. Provide continuous training for our staff on proper operation of our systems and best practices for security and privacy.

Rev.com – All Rights Reserved Page 2

Our security policies and procedures are reviewed on an ongoing basis by the Rev security committee, which is also responsible for enforcement. All our staff have signed confidentiality agreements.

Information Security

Rev.com uses appropriate technical, organizational and administrative security measures to protect any information in its records from loss, misuse, and unauthorized access, disclosure, alteration and destruction. Rev.com uses NIST guidelines and Center for

Internet Security Cybersecurity Best Practices as a foundation for its information security program including information security policies and incident response.

Privacy

Please see the Rev.com Privacy Policy (<https://www.rev.com/about/privacy>) for details of how Rev.com treats personal information and complies with privacy regulations.

Secure Infrastructure

All Rev.com services are hosted by Amazon Web Services (AWS). [AWS maintains strict physical access policies](#) that utilize sophisticated physical access control mechanisms.

Environmental controls such as uninterruptable power and non-destructive fire suppression are integrated elements of all data centers. Rev.com uses multiple geographically distributed data centers as part of a comprehensive disaster recovery

strategy, and uses the CIS Amazon Web Services Benchmarks

(<https://aws.amazon.com/quickstart/architecture/compliance-cis-benchmark/>) as a guide for best practices. AWS provides DDOS services.

Software Development Lifecycle

As a cloud service company, Rev.com releases software frequently and regularly so that clients may benefit from on-going development of new service and security capabilities.

Rev.com – All Rights Reserved Page 3

Rev.com follows a defined SDLC (Software Development Lifecycle) that includes the application of security-by-design principles. Rev operates using an agile development methodology under which software development teams and management are tasked with ensuring that the SDLC method and design principles are followed.

Secure Service Operations

Access to production infrastructure is managed on a least privileges basis and is limited to the Rev.com operations team. Background checks are performed and security training is provided to ensure the background and skills of the operations

staff are consistent with the information security policy and work instructions. Sensitive product service data stored in service databases never leaves the production system and access is controlled according to least privilege principles. Firewalls rules are maintained so that production systems can only be accessed for maintenance from defined Rev.com locations using secured access mechanisms. Systems are maintained in a hardened state with defined baselines for all host and network equipment.

All changes to systems are tracked and managed according to well-established change management policies and procedures. The patch level of third-party software on systems is regularly updated to eliminate potential vulnerabilities.

Breach Detection and Response

Rev.com utilizes network intrusion detection and host integrity management tools to continuously monitor the state of the system. Availability of the system is also continuously monitored using external monitoring tools. System logs are aggregated and archived centrally, facilitating both continuous analysis for suspicious access patterns and future forensic analysis. Regular external vulnerability scanning is also performed.

In the event of a breach, Rev.com has the ability to isolate components of the system to contain the breach and maintain ongoing operations. Rev.com's incident response team is

Rev.com – All Rights Reserved Page 4 at the ready to notify customers of security or service impacting events according to defined notification policies in the Incident Response Plan.

Security Package Contents

The attached Information Security package includes:

1. Rev Information Security Overview (this document)
2. Rev Privacy Policy
3. Rev Terms of Service
4. Rev GDPR Overview
5. Rev Policies
 - a. Encryption Policy
 - b. Third-Party Connection Policy
 - c. Retention Policy
 - d. Network Security Policy
 - e. Incident Response Policy
 - f. Wireless Access Policy
 - g. Password Policy
 - h. Network Access and Authentication Policy
 - i. Mobile Device Policy
 - j. Email Policy
 - k. Acceptable Use Policy
 - l. Physical Security Policy
 - m. Backup Policy
 - n. VPN Policy
 - o. Remote Access Policy

- p. Outsourcing Policy
- q. Guest Access Policy
- r. Data Classification Policy
- s. Confidential Data Policy
- t. Web Application Security Policy
- u. Remote Access Policy
- 6. Rev Procedures (select examples, Rev retains additional confidential procedures)
- Rev.com – All Rights Reserved Page 5
- a. Incident Activity Log Template
- b. Incident Tracking Form
- c. Rev Data Handling 3rd party request procedure
- d. Privacy & Information Security Policy training (high-level example, Rev also requires completion of a 3rd party training platform)
- 7. Rev Data & Security Architecture
- a. Rev Data Flow diagram
- b. Rev Data Subprocessors
- c. Rev Data Flow folder – supporting details
- 8. Rev Qualifications, Certifications and Tests
- a. National Institute of Standards and Technology - Cybersecurity Guidelines
- b. PCI Compliance certificate
- c. Rev PCI Scan Report
- Available on request (our standard legal documents):
- 1. Rev Master Service Agreement (MSA)
- 2. Rev Service Level Agreement (SLA)
- 3. Rev Non-Disclosure Agreement (NDA)
- 4. Rev Data Protection Addendum (DPA)
- 5. Rev Service Agreement