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Current Barriers to Dental Care of Virginia Children With Autism Spectrum Disorder (ASD)

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**CURRENT BARRIERS TO DENTAL CARE OF VIRGINIA CHILDREN WITH
AUTISM SPECTRUM DISORDER (ASD)**

by

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A Thesis Submitted to the Faculty of
Old Dominion University in Partial Fulfillment of the
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MASTER OF SCIENCE

DENTAL HYGIENE

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ABSTRACT

CURRENT BARRIERS TO DENTAL CARE OF VIRGINIA CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD)

Sfair Alkhthami
Old Dominion University, 2019
Director: Prof. Ann Bruhn

Objective: The purpose of this study was to determine the barriers to accessing professional dental care for Virginia children with Autism Spectrum Disorder (ASD) as a mechanism for evaluating dental hygiene curricula. **Methods:** Data was collected via Qualtrics® from caregivers of one or more children with ASD who were part of Families of Autistic Children in Tidewater (FACT). The survey was distributed through FACT to all 200 members (N=200) via an email link, and a response rate of 28.5% (N=57) was obtained. Linear regression and logistic regression models were used to analyze data at the $p=.05$ level of significance. **Results:** Most of the children of the respondents were male (78.95%), Caucasian (63.16%), and an average age of 11 years. A majority of participants' children (92.98%) had dental insurance. Respondents who reported that their children were Caucasian were significantly more likely to receive professional dental care ($p=0.008$). Caregivers of children with ASD who indicated a household income above \$75,000 in the past year were significantly more likely to receive dental treatment compared to those with a reported household income below \$75,000 ($p=0.077$). Children with ASD indicated to have a high level of cooperation, were significantly more likely to receive treatment from a dental professional within the last six months than children who were indicated as uncooperative ($p=0.047$). Caregivers who reported their child had dental anxiety were significantly less likely to receive dental treatment compared to those with a reported low level of dental phobia ($p=0.025$). Interestingly, more than half of participants (59.65%) had not

received dental intervention methods to reduce dental anxiety. **Conclusion:** Results from this study indicate behavior of children with ASD was the main barrier to receiving dental care, including apprehensive behaviors resulting from dental fear. Dental and dental hygiene curricula should include technologies and intervention methods to increase access to dental care in children with ASD; specifically, to address behaviors related to dental treatment fear.

Keywords: Autism Spectrum Disorder, access to dental care, ASD, oral health outcomes, barriers to dental care.

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CHAPTER I

INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong, cognitive disorder characterized by apparent abnormalities in reciprocal social interactions, atypical patterns of communication, repetitive behaviors, and hypersensitivity to external sensory stimuli.¹ The prevalence of ASD in the United States (U.S.) has risen from 1 in 150 in year 2002, to 1 in 59 in year 2018.²⁻

³ According to Johns Hopkins University's Bloomberg School of Public Health, the U.S. rate of ASD has risen 15% over two years.³ Symptoms of ASD can begin as early as six-months of age and become diagnosable around three-years of age.⁴ Symptoms often include delayed language acquisition, echolalia, repetitive behaviors, such as flapping or rocking, and sensory integrative dysfunction.⁴ Aggression in children with ASD is often the result of anxiety and fear surrounding minor changes in the routine and structure of daily life.⁵⁻⁶ A 70% prevalence of aggression toward caregivers was noted in recent research on aggressive behaviors of patients with ASD, and males were found to have higher occurrences of aggression than females.⁷⁻⁸

Hypersensitivity to sensory information is also a common symptom of ASD, including sensitivity to bright lights, painful instruments, loud noises, unfamiliar tastes, and skin contact, and is a major contributing factors leading to disruptive behaviors.⁹⁻¹⁰ These hypersensitivities could present a unique challenge in maintaining oral homecare and receiving dental care.

Children with ASD could present with aggressive behaviors, hypersensitivity, and dental phobia that negatively impact their access to dental services and the quality of care they receive. To date, there is a paucity of information about how these barriers present in the dental services they receive. In addition to the internal barriers that children with ASD experience, there are also external barriers such as dental insurance and family income. Brickhouse et al. found that low

income caregivers were less likely to receive dental care for their children.¹¹ Weiner et al. also found that children with ASD did not receive required preventive dental care when their caregivers had financial burden.¹²

Because of the internal barriers children with ASD present, researchers have studied novel interventions for increasing their access to dental services. As an example, intervention methods such as use of picture cards, mobile applications and video technologies have shown positive effects on children with ASD in reduction of dental anxiety.¹³⁻¹⁵ Information and Communication Technologies (ICTs) allow for the use of autonomous visual and multisensory stimulation, and have been studied with positive results for assisting children with ASD to improve their social interaction and develop skills that could be impossible to obtain without using the subject-technology.¹⁶⁻¹⁹ ICTs may be a useful tool for helping children with ASD to autonomously develop self-control.²⁰ Another assistive technology that may benefit children with ASD, by helping them recognize their emotions and improve their cognitive and social skills, could be the use of virtual reality applications.²⁰ Dental providers can use technologies to help decrease dental anxiety among children with ASD.¹⁸

Statement of the Problem

There are limited studies on children with ASD receiving professional dental care.²¹ One study conducted by Brickhouse et al. assessed the frequency of access to dental care for families of children with ASD and identified some barriers to care for children with ASD in Virginia;¹¹ however, results are difficult to generalize as a low response rate and higher socioeconomic status were obtained and studied. Further, the survey that Brickhouse et al. used did not address whether intervention methods were made available to children with ASD.¹¹ The aim of the present study was to address limitations in the current literature on access to dental care in children with ASD. More specifically, the present research study determined access to care of children with ASD in Virginia and addressed the use of intervention methods within professional dental care. The Brickhouse et al.'s survey was modified to include questions related to barriers to dental care and the prevalence of using intervention methods for children with ASD.¹¹ Implementing a survey for families living in the state of Virginia who have one or more child with ASD and registered within the organization, Families of Autistic Children in Tidewater (FACT), will allow the dental community in Virginia to measure progress in bettering access to dental care for children with ASD. Further work on identifying the main barriers that families of children who have ASD face in accessing dental care for their children could allow increased access to care within the ASD community in Virginia.

This study addressed the following research questions:

1. Has socioeconomic status impacted accessing dental care for the child with ASD?
2. Do children with ASD have dental insurance?
3. Has the child with ASD received intervention methods to reduce dental anxiety?

4. Has the child with ASD's ability to cooperate in the dental setting impacted accessing dental care?
5. Has there been difficulty in accessing dental care for children with ASD who have a dental phobia?

Significance of the Problem

In Virginia, 25% of parents have trouble accessing dental care services for their child with ASD.²² As the number of children with ASD increases, access to dental care must increase in turn. Data analysis will determine the barriers preventing access to dental care for children with ASD. Furthermore, the survey results will highlight the unique needs of the ASD population in Virginia to increase the availability of oral health services for this community. By highlighting the needs of this population, Virginian dental professionals could be better equipped in providing vital oral health services to children with ASD. Data will provide valuable information about the availability of using the intervention methods in the dental setting to reduce dental anxiety among ASD children. The present study will contribute to the body of knowledge regarding the barriers in access to dental care for Virginian children with ASD.

Definition of Terms

For the purpose of this study, the following terms are defined:

- Autism Spectrum Disorder (ASD) - a life-long disorder that affects behavior and communication.²³
- Aggressive behavior – disruptive behavior that involves harming others physically – including hitting, biting, scratching and kicking; behavior that involves harming others non-physically – including yelling, screaming, swearing, and name calling.²⁴

- Unwillingness - being unwilling to serve and/or treat.²⁵
- Cooperative in dental setting -the patient cooperates during treatment without receiving behavior management techniques.²⁶
- Uncooperative in dental setting - the patient requires some behavior management techniques, such as sedation, in the dental setting.²⁶
- Hypersensitivity – an abnormal or exaggerated response to an antigen or allergen.²⁷
- Dental anxiety – excessive fear or emotionality from receiving dental services.²⁸
- Intervention methods - using strategies to manage dental anxiety during dental treatment.²⁹
- Oral health - a state of being free from dental and gum disease.³⁰
- A regular dental checkup – at least annually receiving dental services.³¹
- Local anesthesia - a drug used to manage pain without unconsciousness.³²
- General anesthesia – a drug that involves unconsciousness and prevents the sensation of pain over the entire body.³³
- Sedation -the use of anesthetic drugs to relieve suffering and shorten the procedure time.³⁴
- Dental insurance – insurance that covers dental services for the patient.³⁵
- Income – money earned annually.³⁶
- Accessing dental care - the absence of internal or external barriers in obtaining dental services.³⁷
- Barriers to dental care – internal or external barriers that could prevent or limit people from receiving dental care.³⁷

- Dental Access Survey – the tool used to measure the barriers to accessing dental care for parents of children with Autism Spectrum Disorder.

Null Hypotheses

The following null hypotheses were tested at a 0.05 level of significance:

- 1-There will be no statistically significant difference of accessing dental care in children with ASD based on socioeconomic status as measured by *Dental Access Survey*.
- 2- There will be no statistically significant difference of accessing dental care in children with ASD based on their ability to cooperate in the dental setting as measured by *Dental Access Survey*.
- 3-There will be no statistically significant difference of accessing dental care in children with ASD based on dental phobia as measured by *Dental Access Survey*.

Assumptions

The following assumptions were made regarding this study:

1. The participants of the study will respond to survey questions honestly.
2. The *Dental Access Survey* is a reliable and valid instrument for determining the barriers to care faced by caregivers of one or more children with ASD.
3. The respondents will be caregivers of one or more children with ASD.

CHAPTER II

REVIEW OF THE LITERATURE

A foundation of evidence and support is necessary to present this study. By providing examples of emergent studies as a background, the significance of the topic becomes apparent. This literature review provides a background of the statistical information regarding children with ASD in the United States (U.S.) and Virginia specifically. Additionally, it provides an understanding of the symptomology of aggression presented by individuals with ASD and how this aggression impacts the clinical dental setting. This research addresses a gap in knowledge regarding the barriers to care faced by the caregivers of one or more children with ASD in Virginia and takes a deeper look to reveal and address barriers to dental care for children with ASD.

Prevalence of Children with ASD

Studies on the prevalence of ASD were first conducted in the U.S. in the 1960s where the prevalence was reported as two to four cases per 10,000 children.³⁸ This low prevalence rate led many scientists to believe that ASD was a rare childhood disorder affecting only a few children.³⁸ As of today, the prevalence of ASD is much higher in boys than in girls.³⁹ Since 2014, there has been a 2.4% increase in ASD as compared to 2011-2013 data.⁴⁰ Currently, the U.S. continues to see a sharp increase in the prevalence of ASD,^{2-3,22,40} with an estimated 500,000 to one million children between the ages of six and 17-years living with a diagnosis of ASD.³⁹

A review of the literature did not find information about the specific prevalence rates of ASD in Virginia. However, in 2011, the Virginia Department of Education (VDOE) reported the

percentage of children with ASD enrolled in Virginia public schools in the age range of 6-21 as 1.07% of the enrolled population as compared to .90% of overall national student enrolled population.⁴¹ An epidemiological study has yet to be performed in Virginia to ascertain the exact number of children with ASD.⁴¹ However, national statistics show an upward trend in the prevalence of ASD.³ Therefore, Virginia oral health professionals must be prepared to meet the needs of children with ASD.

Oral Health Status and Access to Care

Children with developmental disorders are reported to have the poorest oral health status and experience disproportionate difficulty in accessing oral health care than their neurotypical counterparts.²⁵ Almost, 15.1% of children with ASD in the U.S. have unmet dental needs.⁴² Studies are conflicting on children with ASD having a higher incidence of oral disease. Specifically, some studies mentioned no different in the prevalence of gingivitis, caries and level of oral hygiene among children with ASD and their peers.⁴⁴⁻⁴⁵ However, some studies found children with ASD having a higher incidence of dental caries compared to regularly developing children.^{6,43} For example, Jaber mentioned that children with ASD had more missing, decayed or filled teeth in comparison to their typically developing peers.⁶ Furthermore, in a study of 61 patients attending Dubai and Sharjah autism centers. Children with ASD had poorer periodontal health status when compared to children without ASD, and 97% of children with ASD had gingivitis.⁶ In another study of 32 children with ASD in Bangkok, 78.1% of the sample had gingival bleeding and 71.9% needed professional cleaning.⁴⁶ Finally, a study of 55 children with ASD conducted in Southern Illinois found that 62% had visible gingivitis.⁴⁷

The oral health status of children with ASD is often negatively impacted by their oral habits. For instance, children with ASD may experience harmful oral habits such as lip biting,

tongue thrusting, and gingival pricking.⁴⁸ Children with ASD have a tendency to present malocclusions, such as crowding and open bite.⁴⁸ Specifically, common malocclusion traits among children with ASD were severe maxillary crowded, posterior crossbite and increased overjet, which put them at risk for dental problems such as dental caries and difficulty with speech.⁴⁹

Access to dental health care is critical to address the poor oral health status of children with ASD. However, low income is a factor that presents as a barrier to accessing dental care for children with ASD.¹¹⁻¹² In a nation-wide cross-sectional study of 1,066 caregivers of children with ASD, about 55% reported difficulty in accessing and using health services.⁵⁰ Roughly one third of caregivers reported inadequate health insurance coverage as a significant barrier.⁵⁰ Additionally, 53% of caregivers reported a financial burden and 38% reported employment challenges as barriers to accessing health services.⁵⁰

Dental care for children with ASD may be restricted due to decreased experiential knowledge among dental professionals regarding the treatment and care for this population.⁵¹ Because children with ASD have significant sensory integration impairment, dental cleanings tend to activate their stress response.⁵⁰ Hypersensitivity to sensory information is commonly seen as a barrier to care in the dental setting.^{7,10} For example, bright lights, painful instruments, loud noises, unfamiliar tastes, and skin contact can be contributing factors that lead to disruptive behavior in patients with ASD.¹⁰ Another significant contributing factor to the barriers in the dental setting are dental anxiety and dental phobia.¹⁰ Dental phobia can increase hypersensitivity in the patient with ASD due to the aggravation of the sensitive sensory integration impairment.¹⁰ In a sample of 196 parents of children with ASD in South California, approximately 61% reported challenges during at-home oral routines, as well as in-office dental cleanings and oral

examinations.^{10,25} Lack of cooperation among children with ASD could provide challenges to dental providers; as such, many of them are unwilling to serve and treat children with ASD.²⁵ Children with ASD are more likely to have longer lengths of time between dental appointments due to a significant pronouncement of barriers to dental care.⁵²

Characteristics of Children with ASD

Characteristics of children with ASD include delayed language acquisition, echolalia, engagement in repetitive behaviors, such as flapping or rocking, and sensory integrative dysfunction.⁴ Also, almost 75% of children with ASD exhibit moderate intellectual impairment.⁵³ Further, hyperactivity, anxiety and aggressiveness are common behavioral characteristics of children with ASD.⁴⁸ For instance, aggression is often a barrier to care for children with ASD.⁵⁴ Aggression in children with ASD is often the result of minor changes in the routine and structure of daily life and is the result of anxiety and fear surrounding these changes.⁵⁻⁶ Typical behavioral outbursts displayed by individuals with ASD include tantrums, aggression toward self or others, screaming, verbalizations, inappropriate anxiety, fear, and irritability.^{8,54} Farmer et al. discovered a 70% prevalence of aggression toward caregivers in their research on aggression behaviors in patients with ASD.⁸ Physical aggression such as kicking, biting, throwing items, and hitting, as well as self-injurious behaviors were the most commonly observed aggressive behaviors.⁷

Hostile and aggressive behavior among patients with ASD is common and could limit care in the clinical setting.⁸ Inappropriate behaviors are often identified as “the greatest barrier to general dentists’ willingness to treat children with disabilities...” (p.2).¹⁰ Additionally, 60–80% of dental providers mentioned that resistive behaviors among people with developmental disabilities made them are unwilling to treat those patients.¹ These uncooperative behaviors are expressed as self-injurious behaviors, verbally aggressive outbursts, or can be expressed through

physical aggression.^{6,10} In addition to hostility and aggression, anxiety symptoms are also problematic when treating children with ASD in dental settings. Roughly 40% of children with ASD are diagnosed with a comorbid anxiety disorder which can impact their behavior negatively.⁵⁵ Also, the child's anxiety may increase when the child is treated in the dental setting, which could make the procedure of dental hygiene treatment complicated due to anxiety related behavioral outbursts.⁵⁶ Further, children with ASD presenting with hypersensitivity to sensory information may create challenges in dental settings when they receive dental care.^{7,9} Because of atypical responses to sensory input, behavioral outbursts may occur due to miscommunications between the child with ASD and the dental care professionals.⁵⁷ Children with ASD can face difficulty when they have a dental hygiene appointment because they are unfamiliar with the dental providers and dental setting.⁵⁶ Children with ASD have significantly higher instances of uncooperative behavior during oral health routines; therefore, collaborating with parents to create a plan tailored to the child, could minimize the aggressive behavior.⁵⁸ Since the aim of the first appointment is to develop a relationship with the child, a prior visit could be useful for caregivers and dental providers because it could help the parents to prepare their children for dental treatment.^{48,59}

Limited communication is described as a significant contributing factor to aggressive behavior.¹⁰ Because of the inability to communicate functionally, children with ASD have often not learned self-coping mechanisms like cognitive self-talk (e.g. "this will be over soon," or "this is necessary because it is good for my teeth") that neurotypically developing children have learned.¹⁰ The inability of children with ASD to calm themselves during dental cleanings leads to increased behavioral distress and physiological stress.¹⁰

Intervention Methods

Decreased communication, anxiety and hypersensitivity could make dental treatment too difficult to carry out without assistive technologies for children with ASD.⁵⁶ Most relevant technologies and applications have shown very positive results when they were used to work on key areas impacted by the disorder.^{18,60} Using intervention methods such as picture cards, mobile applications and video technologies, has shown positive effects on children with ASD in reducing dental anxiety, leading to greater acceptance of dental hygiene treatment.¹³⁻¹⁵ Virtual reality applications have shown good results when they were used as therapeutic tools to help children with ASD to recognize emotions and improve their cognitive skills.²⁰ Applying communicative devices in the dental setting could provide easier communication for children with ASD.⁴⁸ One such assistive technology is the Picture Exchange Communication System (PECS), which is used by those with little or non-verbal communication skills as an alternative communication technique.⁴⁸ PECs is a book of pictures that allow non-verbal children with ASD to express their desires, observations, and feelings through pictures.⁴⁸ Also, using “Tell-Show-Do” is an effective therapy tool to introduce dental treatment procedures or dental equipment and instruments to a patient with ASD.⁶¹ A well-adapted dental environment plays a role in reducing discomfort among children with ASD.⁶² For example, images of radiographs, saliva ejectors and plastic mouth mirrors could be used to explain what will happen next when dental professionals make use of the “Tell-Show-Do” method. Children with ASD could benefit from practicing some aspects of a dental treatment procedure before having them in dental setting.⁴⁸ Eades et al. mentioned that more than forty percent (40.9 %) of dental providers reported that they were not aware of intervention methods and techniques which could be helpful when treating children with ASD.⁶³ When children with ASD visit the dental setting, it is important for dental professionals to demonstrate empathy, willingness to care and patience to communicate.⁴⁸

Using distraction techniques, such as watching a cartoon, could help children with ASD by distracting them from their sensitivities during some dental treatment procedures.⁴⁸ Taste and auditory stimuli could be decreased by using sensory techniques such as choosing a toothpaste with an acceptable taste.⁴⁸ Because most children with ASD are visual learners, using visual pedagogy could reduce apprehension by teaching children with ASD the skills necessary to undergo professional dental care, which allows them to know the sequence of procedures.^{48,64}

In summary, steps to increase the adaptiveness of the dental environment to fit the needs of children with ASD should be taken to ensure that this population can access and receive dental care more easily. Increasing the availability of beneficial tools that reduce anxiety, sensitivity, uncooperative behaviors, and aggressiveness that work by familiarizing them with dental setting could assist in building trusting relationships between dental clinicians and children with ASD. Also, using intervention methods for children with ASD to increase their social skills and cooperation in the dental setting may further aid this goal. The aim of this study was to obtain information on barriers that could prevent children with ASD from accessing dental care in Virginia, and to know if the intervention methods were used and whether they were useful. Currently, limited studies are available on barriers that could prevent children with ASD from accessing dental care in Virginia; however, there is no study focused on barriers and using intervention methods. Data analysis could help children with ASD access dental care and help dental professionals provide dental care.

CHAPTER III

METHODOLOGY

This study received exempt status by the Old Dominion University (ODU) College of Health Sciences (COHS) Institutional Review Board (IRB) for the protection of human subjects. The survey selected for this study was a modified mixed open/closed questionnaire initially developed by Agili et al. and later modified by Brickhouse et al.^{65,11} The questionnaire, “*Dental Access Survey*,” was further modified in the present study and re-validated through implementation with three special education faculty members at Old Dominion University who also have children with ASD. The final modified version of the “*Dental Access Survey*” was distributed to the target population, caregivers of one or more children with ASD who are members of Families of Autistic Children in Tidewater (FACT), using the University-based survey system Qualtrics. The survey was distributed to 200 members of FACT (N=200) through an email sent by the organization with a link to the survey with a targeted response rate of 25% or 50 respondents. The inclusion criteria required respondents be a caregiver with one or more children with ASD ages 3-17 years and registered with FACT. The members were reminded weekly with a time period of one month to complete the survey, and their responses were made anonymous by using a double-blind method.

An explanation of the purpose of the study, subjects’ confidentiality, time to complete the survey, instructions to complete the survey, inclusion criteria, exclusion criteria, and emails to contact for questions or rights as a research participant were included in a survey cover letter. Participants were also informed through the survey cover letter that the participation in this study could be helpful to obtain and generate new knowledge in order to improve health outcomes among Virginia children with ASD and advance the dental hygiene profession. The survey

included 30 questions: eight related to demographics, eleven oral hygiene, five to dental professional care, one child's behavior, two barriers accessing dental care, and three intervention methods. The questions were Likert scale, cumulative, dichotomous and contingent.

Statistical Analysis Software (SAS®) version 9.4 was used to perform statistical analysis. Simple linear regression, logistic regression models, and descriptive statistics were used to analyze data for statistical significance and distribution differences. The researchers indicate with 95% confidence that the expected value is significant at $\alpha = .05$ if appropriately found and differences between levels are computed by testing all null hypotheses at .05 level of significance.

CHAPTER IV

RESULTS

The survey was sent to 200 members of the FACT organization and 57 surveys were returned and deemed valid for analysis, resulting in a response rate of almost one third of members (28.5%). One survey was excluded since the participant had a child that did not meet the inclusion criteria age requirement. Most of the children of the respondents were male (78.95%), Caucasian (63.16%), with an average age of 11 years. Additionally, 33.33% were African American, mixed Race and other (non-Caucasian), and two respondents did not provide a response to the question regarding race. A majority of participants' relationship to the child was parent (89.47%) while the remaining indicated legal guardian. Almost half of the participants were full-time employees (50.88%) while 49.12% of participants were part-time employees, retired, student, homemaker, and other. Almost half of respondents (49.12%) had a high income annually (\geq \$75,000), while 20.35% reported a low income ($<$ \$75,000). The sample population's demographics are summarized in Table 1.

Table 1. Demographic Statistics for the Sample (N=57)

| Demographic Checklist | <i>n</i> | % |
|-----------------------------|----------|-------|
| Gender | | |
| Male | 45 | 78.95 |
| Female | 12 | 21.05 |
| Total | 57 | 100 |
| Age | | |
| ≤ 11 | 29 | 50.88 |
| > 11 | 26 | 45.61 |
| Missing | 2 | 3.51 |
| Total | 57 | 100 |

Table 1. (continued)

| Demographic Checklist | <i>n</i> | % |
|---------------------------|----------|-------|
| Race | | |
| White | 36 | 63.16 |
| Non-white | 19 | 33.33 |
| Missing | 2 | 3.51 |
| Total | 57 | 100 |
| Relationship | | |
| Parent | 51 | 89.47 |
| Legal guardian | 6 | 10.53 |
| Total | 57 | 100 |
| Employment | | |
| Employed full-time | 29 | 50.88 |
| Employed part-time | 7 | 12.28 |
| Retired | 5 | 18.77 |
| Student | 1 | 1.75 |
| Homemaker | 14 | 24.56 |
| Other | 1 | 1.75 |
| Total | 57 | 100 |
| Income | | |
| ≥ \$75,000 | 28 | 49.12 |
| < \$75,000 | 23 | 20.35 |
| Missing | 6 | 10.53 |
| Total | 57 | 100 |

The survey showed that 73.68% of children with ASD received professional dental care within the last six months. Most children with ASD were reported to have a dental checkup scheduled for within the next 12 months. The majority of the participants also reported a travel time of no more than 30 minutes to receive professional dental care. Also, most caregivers reported (84.21%) having a professional dentist for oral health care and over 80% of respondents indicated their child with ASD was currently scheduled for a checkup within the year. However, 68.42% of the caregivers of children with ASD mentioned that having ASD posed a barrier to dental care as seen in Table 2.

Table 2. Frequencies and Percentages of Access Characteristics

| Access Measurements | <i>n</i> | % |
|--|-----------|------------|
| Time since last visit to dental clinic | | |
| Within the last 6 months | 42 | 73.68 |
| 6+ months to 1 year ago | 10 | 17.54 |
| 1+ to 2 years ago | 3 | 5.26 |
| 2+ to 4 years ago | 2 | 3.51 |
| Total | 57 | 100 |
| Has a dentist for periodic oral care | | |
| Yes | 48 | 84.21 |
| No | 6 | 10.52 |
| Missing | 3 | 5.26 |
| Total | 57 | 100 |
| Currently scheduled for checkup in the next 12 months | | |
| Yes | 49 | 85.96 |
| No | 8 | 14.04 |
| Total | 57 | 100 |
| Reason why not scheduled for a checkup | | |
| I cannot find a dentist with special skill | 3 | 37.50 |
| Insurance does not cover dental services | 1 | 12.50 |
| Insurance does not cover & No Medicaid Waiver Program | 1 | 12.50 |
| Other reasons | 3 | 37.50 |
| Total | 8 | 100 |
| Travel Time | | |
| < 30 mins | 41 | 71.93 |
| 30 mins to 1 hrs | 14 | 24.56 |
| 1-2 hrs | 1 | 1.75 |
| Missing | 1 | 1.75 |
| Total | 57 | 100 |
| Ever refused treatment | | |
| Yes | 9 | 15.79 |
| No | 48 | 84.21 |
| Total | 57 | 100 |
| Having ASD posed a barrier | | |
| Yes | 39 | 68.42 |
| No | 17 | 24.56 |
| Missing | 1 | 1.75 |
| Total | 57 | 100 |

Less than 50% of children with ASD were reported by their caregivers as brushing their teeth more than once a day. The majority of caregivers of children with ASD (87.72%) stated that their children required assistance to brush their teeth (Table 3), and almost two thirds of the caregivers (61.40%) did not face any difficulty assisting their children to brush.

Table 3. Frequencies and Percentages of Current Oral Hygiene Care

| Brushing Teeth Checklist | <i>n</i> | % |
|--|-----------------|----------|
| Brushing teeth without assistance | | |
| More than once a day | 28 | 49.12 |
| Once a day | 20 | 35.09 |
| 2-6 times a week | 3 | 5.26 |
| Once a week or less frequently | 5 | 8.77 |
| Do not know | 1 | 1.75 |
| Total | 57 | 100 |
| Require assistance to brush | | |
| Always | 13 | 22.81 |
| Most of the time | 12 | 21.05 |
| Some of the time | 14 | 24.56 |
| Rarely | 11 | 19.30 |
| Never | 7 | 12.28 |
| Total | 57 | 100 |
| Difficult to brush or assist | | |
| Yes | 21 | 36.84 |
| No | 35 | 61.40 |
| Missing | 1 | 1.75 |
| Total | 57 | 100 |
| How difficult to brush or assist | | |
| Easy | 0 | 0 |
| Somewhat easy | 1 | 4.76 |
| Somewhat difficult | 15 | 71.43 |
| Very difficult | 5 | 23.81 |
| Total | 21 | 100 |

Most caregivers of children with ASD (92.98%) reported their children had dental insurance as seen in Table 4. Almost all of caregivers of children with ASD reported that their children received professional dental cleaning and checkups (96.49%). Table 4 shows more than half of caregivers of children with ASD (54.39%) indicated their children spent more than 30 minutes receiving professional dental care. Differences were observed between the setting in which routine work, such as dental cleanings and checkups took place, and where dental treatments such as dental fillings occurred. Dental cleanings and checkups predominately occurred in dental offices (96.49%); only 3.51% occurred in hospitals. Conversely, less than half of dental treatments took place at dental offices (49.12%), and almost a quarter occurred at hospitals (19.30%).

Table 4. Frequencies and Percentages of Dental Procedures

| Dental Procedures | <i>n</i> | % |
|--------------------------------|----------|-------|
| Dental insurance | | |
| Yes | 53 | 92.98 |
| No | 4 | 7.02 |
| Total | 57 | 100 |
| Cleaning and checkups | | |
| Dental office | 55 | 96.49 |
| Hospital | 2 | 3.51 |
| Total | 57 | 100 |
| Dental treatments | | |
| Dental office | 28 | 49.12 |
| Hospital | 11 | 19.30 |
| Other | 2 | 3.51 |
| Missing | 16 | 28.07 |
| Total | 57 | 100 |
| Time of dental cleaning | | |
| 1-30 minutes | 26 | 45.61 |
| 31-60 minutes | 25 | 43.86 |
| 61-90 minutes | 6 | 10.53 |
| Total | 57 | 100 |

Among the caregivers, over seventeen percent (17.54%) reported that their child required oral medication when receiving professional dental care. More than seventeen percent (17.54%) additionally reported that their child required general anesthesia. Together, children requiring oral medication and general anesthesia amounted to almost half of the sample population (41.35%). More than half of the participants, reportedly, did not require anesthesia (59.65%). Less than six percent (5.26%) required local anesthesia, according to the caregivers.

Table 5. Frequencies and Percentages of Children with ASD Requiring Anesthetic During Dental Treatment

| Required Anesthetic | n | % |
|---|----------|----------|
| May require some form of oral medication to make child sleepy. | 10 | 17.54 |
| No anesthesia required. | 34 | 59.65 |
| Requires general anesthesia (having child put to sleep) due to being extremely uncooperative. | 10 | 17.54 |
| Requires only local anesthetic, sometimes enhanced by a sedative taken prior to the appointment. | 3 | 5.26 |

More than half of caregivers of children with ASD reported their children did not receive dental interventions to reduce dental anxiety prior to professional dental care (59.65%). Less than forty one percent (40.35%) of the children with ASD received different intervention methods such as picture cards, mobile applications and video technologies. For those who did receive intervention methods, mobile application and video technologies were used more than other methods. Out of those that indicated their child with ASD did receive an intervention

method to help with professional dental care, 91.30% indicated the intervention method was useful to reduce dental anxiety (Table 6).

Table 6. Frequencies and Percentages of Using Intervention Methods

| Intervention Descriptive | <i>n</i> | % |
|---|-----------------|----------|
| Has received intervention | | |
| Yes | 23 | 40.35 |
| No | 34 | 59.65 |
| Total | 57 | 100 |
| Intervention was used | | |
| Mobile applications | 2 | 8.70 |
| Picture cards | 3 | 13.04 |
| Picture cards and Mobile application | 1 | 4.35 |
| Picture cards and video technologies | 1 | 4.35 |
| Picture cards, video technologies, and other | 1 | 4.35 |
| Picture cards and other | 3 | 13.04 |
| Video technologies and Mobile application | 3 | 43.86 |
| Other | 9 | 39.13 |
| Total | 23 | 100 |
| Was using intervention helpful | | |
| Yes | 21 | 91.30 |
| No | 2 | 8.70 |
| Total | 23 | 100 |

The majority of caregivers of children with ASD (57.90%) indicated their children were uncooperative in the dental setting, and 59.65% of them had dental phobia. Levels of cooperation and dental phobia have been provided in Table 7.

Table 7. Frequencies and Percentages for Behavioral Characteristics Among Children With ASD

| Dependent Characteristics | <i>n</i> | % |
|--------------------------------|----------|-------|
| Cooperation | | |
| Cooperative | 23 | 40.35 |
| Somewhat Cooperative | 22 | 38.60 |
| Extremely uncooperative | 11 | 19.30 |
| Missing | 1 | 1.75 |
| Total | 57 | 100 |
| Dental phobia | | |
| Not fearful | 20 | 35.09 |
| Fearful | 34 | 59.65 |
| Missing | 3 | 5.26 |
| Total | 57 | 100 |

In addition, a majority of caregivers of children with ASD (75.44%) reported that having additional mental or physical conditions did not pose a barrier for children to receive dental care (Table 8).

Table 8. Frequencies and Percentages of Respondents' Indication to Mental and Physical Conditions

| Mental and Physical Conditions | <i>n</i> | % |
|---|----------|-------|
| Do mental and physical conditions pose a barrier | | |
| Yes | 14 | 24.56 |
| No | 43 | 75.44 |
| Total | 57 | 100 |

Simple Linear regression

$$E(Y|X) = \beta_0 + \beta_1 X$$

where $Y = \log(LDV + 0.5)$, and LDV is the dependent variable and X is independent variable and is one of the following variables: cooperation, dental phobia, income, and race.

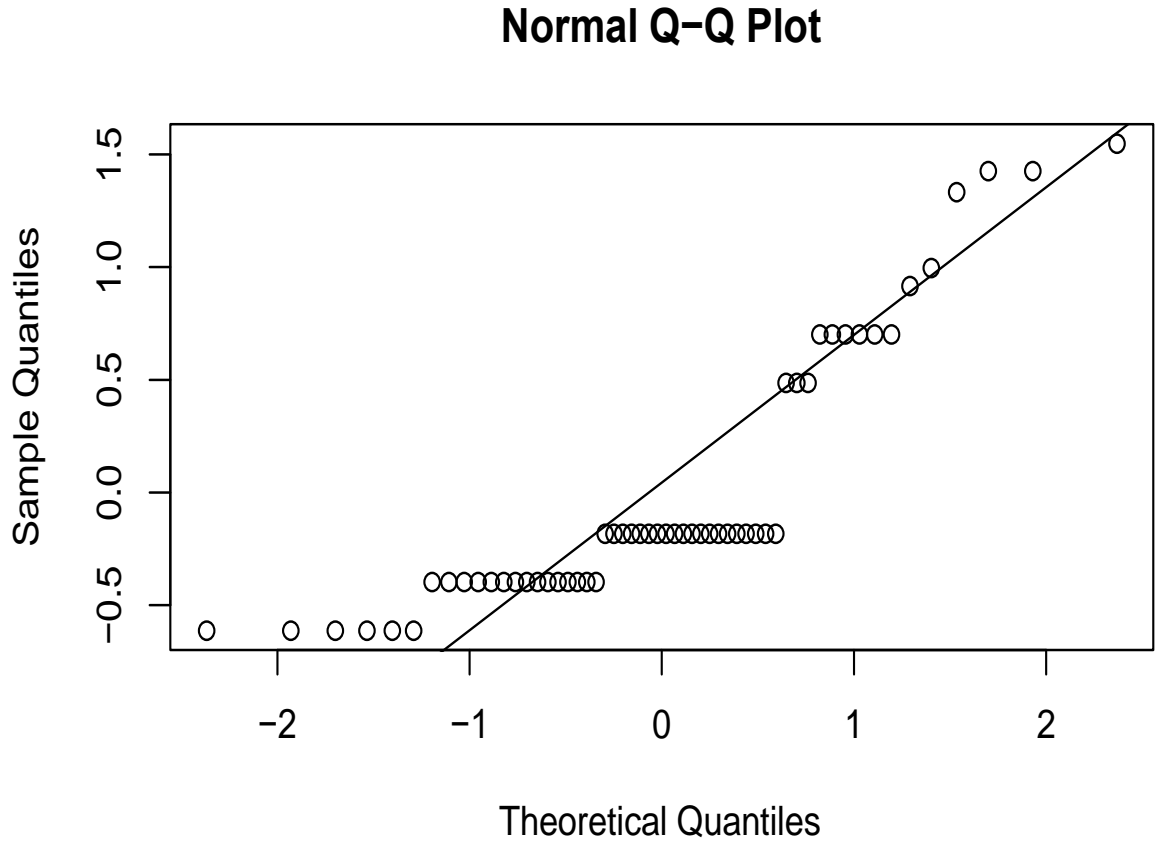
Regression of dental visit versus selected independent variables was analyzed.

Respondents who indicated that their children with ASD had a high level of cooperation, were significantly more likely to have received treatment from a dental professional within the last six months than children who were indicated as uncooperative ($p=0.047$) as seen in Table 9. Figure 1 shows the quantiles plot, a scatter plot of cumulative sample and theoretical to assess assumptions of normality. Visual inspection may challenge that assumption, as the points do not fall on a 45° angle line; however, we also considered other models. The estimate was positive (.21), meaning that when children's cooperation was high, the access to dental care was 21% higher than a child who was uncooperative. There was no statistically significant difference regarding dental phobia, income and race. The results suggested that income was not statistically significant while the estimate was negative (-0.03) with p-value 0.864.

Table 9. Significance Levels Between Children's Individual Characteristics and their Last Dental Visit

| | | Last Dental Visit (LDV) | | | | |
|----------------------------|-----------------------------|-------------------------|------|----------------|----------------|---------|
| Individual Characteristics | | Mean | SD | β_0 (SE) | β_1 (SE) | P-value |
| Cooperation | Cooperative (1) | 0.29 | 0.68 | -0.73(0.21) | 0.21(0.10) | 0.047** |
| | Somewhat uncooperative (2) | 0.35 | 0.78 | | | |
| | Extremely uncooperative (3) | 0.80 | 1.03 | | | |
| Dental phobia | Not fearful (1) | 0.42 | 0.75 | -0.39(0.29) | 0.03(0.17) | 0.864 |
| | Fearful (2) | 0.43 | 0.85 | | | |
| Income | \geq \$75,000 (1) | 0.46 | 0.69 | -0.31(0.13) | -0.03(0.17) | 0.886 |
| | < \$75,000 (0) | 0.38 | 0.90 | | | |
| Race | White (1) | 0.48 | 0.91 | -0.43(0.14) | 0.12 (0.17) | 0.482 |
| | Non-White (0) | 0.33 | 0.61 | | | |

Figure 1. Plot of Sample and Theoretical Quantiles for Cooperation and Last Dental Visit



Simple Logistic regression

$$\log\left(\frac{P(Y = 1)}{1 - P(Y = 1)}\right) = \beta_0 + \beta_1 X$$

Or

$$P(Y = 1) = \frac{\exp(\beta_0 + \beta_1 X)}{1 + \exp(\beta_0 + \beta_1 X)}$$

Where Y is the perception that ASD is the main barrier to receive professional dental care, i.e. the dependent variable and X is independent variable and is one of the following variables: cooperation, dental phobia, income, and race.

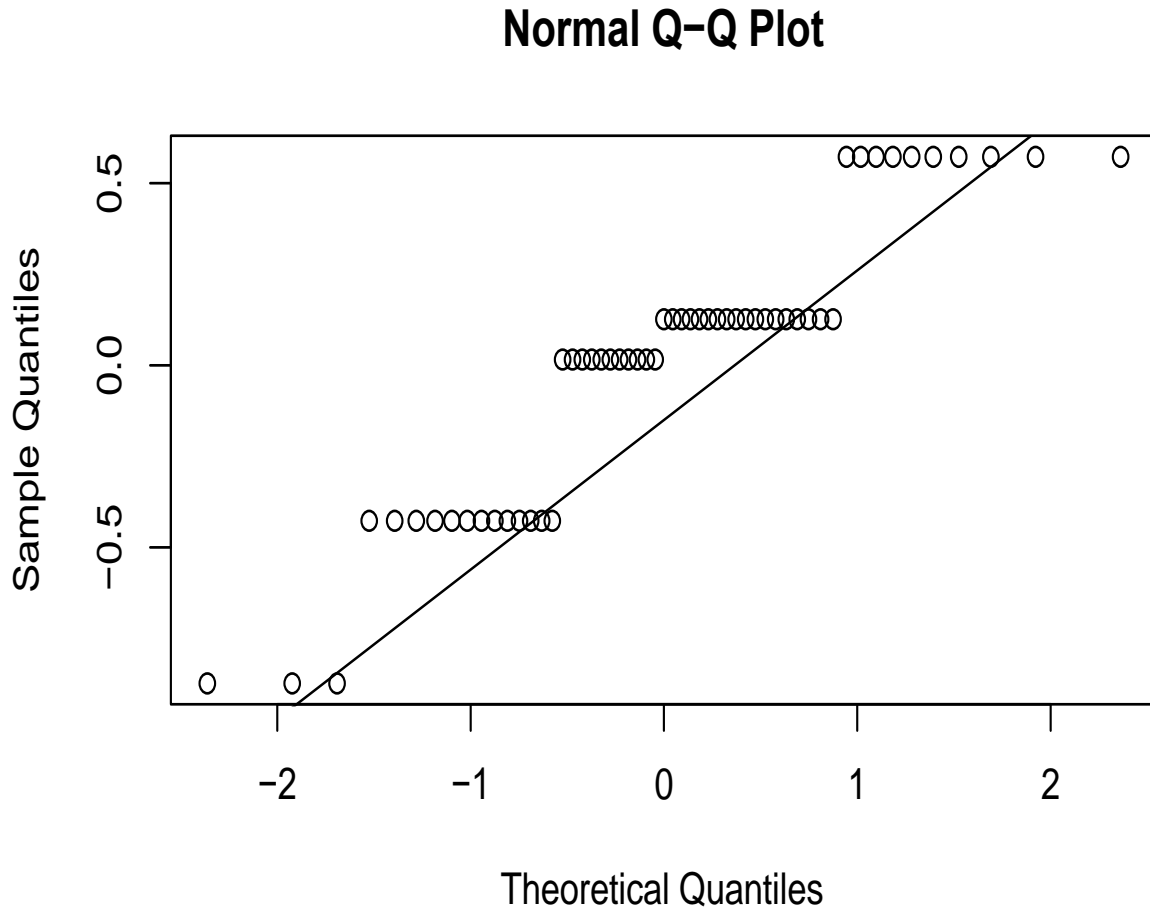
Logistic regression model was good to use to find the relationship between the independent variables and the binary outcomes. All the independent variables showed significance for the simple logistic regression model as seen in Table 10. Respondents who reported that their children were Caucasian were significantly more likely to receive professional dental care ($p=0.008$). The odds of having a barrier to dental care when having ASD was approximately $e^{1.68} = 5.37$ greater for non-Caucasian patients than Caucasian patients. Caregivers of children with ASD who indicated a household income above \$75,000 in the past year were significantly more likely to receive dental treatment compared to those with a reported household income below \$75,000 ($p=0.077$). The odds of having a barrier to dental care when having ASD was about $e^{1.16} = 3.18$ greater for those with lower income when compared to those with higher income. Respondents who indicated that their children with ASD had a high level of cooperation, were significantly more likely to receive treatment from a dental professional than children who were indicated as uncooperative ($p=0.001$) as shown in Figure 2. The odds of having a barrier to dental care when having ASD was about $e^{2.22} = 9.23$ greater for the somewhat uncooperative patients when compared to the cooperative patients. Also, the odds of having a barrier to dental

care when having ASD was about 85.33 greater for the extremely uncooperative patients when compared to the cooperative patients. Caregivers who reported their child had dental anxiety were significantly less likely to receive dental treatment compared to those with a reported low level of dental phobia ($p=0.025$). The odds of having a barrier to dental care when having ASD was about $e^{1.44} = 4.2$ greater for fearful patients when compared to the not fearful ones.

Table. 10 Significance Levels Between Children’s Individual Characteristics and ASD Posed Barriers to Dental Care

| Having ASD Poses Barriers to Dental Care | | | | | | |
|--|-----------------------------|------|------|----------------|----------------|----------|
| Individual Characteristics | | Mean | SD | β_0 (SE) | β_1 (SE) | P-value |
| Cooperation | Cooperative (1) | 0.47 | 0.51 | -2.52(0.98) | 2.22(0.69) | 0.001*** |
| | Somewhat uncooperative (2) | 0.94 | 0.24 | | | |
| | Extremely uncooperative (3) | 1.00 | 0.00 | | | |
| Dental phobia | Not fearful (1) | 0.57 | 0.51 | -1.33(1.03) | 1.44 (0.64) | 0.025** |
| | Fearful (2) | 0.86 | 0.34 | | | |
| Income | \geq \$75,000 (1) | 0.81 | 0.46 | 0.37(0.43) | 1.16(0.66) | 0.077* |
| | < \$75,000 (0) | 0.72 | 0.40 | | | |
| Race | White (1) | 0.86 | 0.35 | -0.11(0.46) | 1.68 (0.64) | 0.008*** |
| | Non-White (0) | 0.60 | 0.51 | | | |

Figure 2. Plot of Sample and Theoretical Quantiles for Cooperation and ASD Posed Barriers to Dental Care



CHAPTER V

DISCUSSION

The results of the present study show that children with ASD in minority race groups had barriers to dental care; however, this finding could be as result of sampling error since most of the participants were Caucasian. Caregivers of children with ASD who indicated a low household income in the past year were significantly less likely to have access to dental care. This finding is consistent with Brickhouse et al. which found that low income caregivers were less likely to receive dental care for their children.¹¹ Furthermore, if caregivers of children with ASD experience financial burdens, there could be a negative effect on accessing dental care for their children. Similarly, Weiner et al. found that when caregivers of children with ASD had financial burden, their children did not receive required preventive dental care.¹²

Cooperation was one of the main barriers to dental care as reported by caregivers in the present study, which was also found in Dover and Couteur.¹ Dover and Couteur cited a lack of cooperative behaviors as the leading reason for denying dental care services to children with ASD.¹ Specifically, uncooperative behaviors during oral health routines were exhibited by children with ASD⁵⁸ which could lead to challenges for dental providers.²⁵ A small number of caregivers of children with ASD mentioned that their children were refused dental professional treatment as a result of lack of cooperation from their children. Similarly, Brickhouse et al. observed that children who were uncooperative with their dental services were noted as not having a regular dental provider.¹¹ Because the uncooperative behaviors that children with ASD exhibit impact dental providers' willingness to serve them, dental providers should be better trained to respond to and manage their behaviors.

After analyzing the data of 57 participants, a majority of participants' children (92.98%) had dental insurance; however, almost one third did not visit a dental clinic within the last six months. Most children with ASD in this study were reported to have spent more than 30-minutes in the dental clinic receiving professional dental care. The majority of caregivers reported challenges during at-home oral routines and also during in-office dental cleanings and oral examinations.^{10,25} Respondents who indicated that their children with ASD had a high level of cooperation were more likely to receive dental treatment than those who were uncooperative. Most children with ASD reported to have a dental checkup scheduled for the next 12 month and a travel time from home to dental clinic of less than 30-minutes. Most of the children with ASD also reported to have a professional dental provider for oral health care and were never refused dental treatment. However, caregivers of children with ASD, especially those who did not schedule their children for professional dental care, or their children were refused to be treated, reported that not finding a dental provider with special skills was the main reason preventing their children from scheduling professional dental services.

At times, dental providers are not willing to treat children with ASD especially those with resistive behavior. Resistive behaviors among people with developmental disabilities made most dental providers unwilling to treat those patients.¹ Most caregivers reported that their child had dental anxiety and indicated this as a barrier to dental professional care. Caregivers who reported their child had dental anxiety were less likely to receive dental treatment compared to those with a reported low level of dental phobia ($p=0.025$). When the child is treated in the dental setting, anxiety could make the procedure of dental hygiene treatment complicated or impossible for children with ASD.⁵⁶ Dental anxiety among children with ASD could prevent them from receiving dental care and anxiety is a significant contributing factor to the barriers in the dental

care for patients.¹⁰ Therefore, information and training are needed for dental professionals so that they will be prepared to effectively respond to behavior characteristics (i.e. uncooperative behaviors) of children with ASD. Because this study found that almost half the children with ASD required oral medication or general anesthesia to increase their cooperation with dental care, dental professionals should be better informed regarding non-medication alternatives for managing this population. In this study, it is conceivable that interventions may have been useful in helping the participants to develop skills that would have reduced the need for medication to make them more cooperative.

More than half of children with ASD had not received dental intervention methods to reduce dental anxiety as reported by caregivers. Most caregivers, especially those who received intervention methods for their children, believed using intervention methods were useful to reduce dental anxiety among their children. Dental professionals should be trained to use intervention methods that help children with ASD to access dental and dental hygiene treatment services without facing difficulties. Use of the assistive technologies for children with ASD improves communication, reduces anxiety and hypersensitivity and could allow children with ASD to receive dental treatment with less anxiety.⁵⁶ The lack of experiential knowledge among dental professionals regarding the treatment and care needed for ASD patients could restrict them in providing the required dental care.² Most children with ASD have behavioral characteristics such as aggression and anxiety. Patients with ASD have common behavioral characteristics of hyperactivity, anxiety and aggressiveness,⁴⁸ which poses a significant barrier to accessing dental care.⁵⁴ As such, dental professionals should have special skills and learn more about behavioral characteristics among children with ASD to facilitate their treatment.

Using Intervention Methods

Using intervention methods such as picture cards, mobile applications and video technologies could reduce dental anxiety among children with ASD. Positive effects were reported when intervention methods were used to reduce anxiety which lead to greater acceptance of dental hygiene treatment.¹³⁻¹⁵ Interestingly, most of caregivers of children with ASD in Virginia reported that their children did not receive dental intervention methods to reduce dental anxiety. This result indicates that some dental providers in Virginia did not know about the benefits of using intervention methods. More than forty percent (40.9 %) of dental providers reported that they were not aware of techniques and intervention methods which could be helpful when treating children with ASD.⁶³

Almost all caregivers of children with ASD who received intervention methods for their children, reported that receiving intervention methods were helpful to reduce dental anxiety. This finding corresponds with past studies, which have shown that using interventions to enhance dental services for children with ASD enhances outcomes in this population.¹³⁻¹⁵ Intervention methods should be used to reduce dental anxiety among children with ASD. Dental providers should use recent applications and technologies to facilitate dental treatment for children with ASD. Most relevant technologies and applications have shown very positive results when they are used to work on key areas impacted by the disorder.^{18,60}

Dental providers could use intervention methods to increase their social skills and cooperation among children with ASD in dental clinic. Communication with the child with ASD becomes easier when applying communicative devices in the dental setting.⁴⁸ Dental professionals could also receive training on the use of virtual applications because they are useful therapeutic tools. When virtual reality applications are used as therapeutic tools to assist during dental

treatment, children with ASD improve their cognitive skills and emotions.²⁰ Dental professionals should be aware of these tools for meeting the dental needs of children with ASD and improving their dental outcomes.

Limitations

The internal and external validity of this study could be affected by:

1. A convenience sample of 200 children with ASD resulted in a low response rate, however, having 57 participants is considered a good number especially for this population.
2. Survey responses may not be accurate because the parent/guardian did not want to mention their child's behaviors or their income.
3. The survey questions did not cover other medical issues faced by ASD children.
4. The study is limited to Virginia population.

CHAPTER VI

CONCLUSION

While the number of children with ASD increases, access to dental care should increase in turn. Dental professionals should emphasize the importance of oral hygiene to caregivers of children with ASD. Results from this study indicate that having ASD poses barriers to dental care due to behaviors associated with the disorder and lack of special skills among dental care providers. Most children with ASD were uncooperative in the dental setting; therefore, dental professionals should have increased training on innovative technologies to treat children with ASD in an appropriate way. Results from this study showed that children with ASD with dental phobia did not receive intervention methods to reduce dental anxiety.

More research is needed to measure the effectiveness of using intervention methods among children with ASD and to explore training of dental professionals to treat children with ASD. Dental professionals should be trained in their workplace to use technologies and intervention methods to reduce dental anxiety among children with ASD. Dental and dental hygiene curricula also could include technologies and intervention methods to increase access to dental care in children with ASD to specifically address behaviors related to dental treatment.

REFERENCES

1. Dover CJ, Couteur AL. How to diagnose autism. *Arch Dis Child* 2007Jan;92(6):540–5.
2. Baio J, Wiggins L, Christensen DL, Maenner MJ, Daniels J, Warren Z, et al. Correction and Republication: Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *MMWR*. 2018;67(45):1279.
3. U.S. autism rate up 15 percent over two-year period [Internet]. ScienceDaily. CDC; 2018. Available from: <https://www.sciencedaily.com/releases/2018/04/180426141604.htm>
4. Learn the Signs [Internet]. Autism Speaks. [cited 2018Oct3]. Available from: <https://www.autismspeaks.org/learn-signs>
5. Karande S. Autism: A review for family physicians. *Indian J Med Sci*. 2006;60(5):205.
6. Jaber MA. Dental caries experience, oral health status and treatment needs of dental patients with autism. *J Appl Oral Sci*. 2011;19(3):212–7.
7. Matson JL, Adams HL. Characteristics of aggression among persons with autism spectrum disorders. *Res. Autism Spectr. Disord*. 2014;8(11):1578–84.
8. Farmer C, Butter E, Mazurek MO, Cowan C, Lainhart J, Cook EH, et al. Aggression in children with autism spectrum disorders and a clinic-referred comparison group. *Autism*. 2014Apr;19(3):281–91.
9. Leekam SR, Nieto C, Libby SJ, Wing L, Gould J. Describing the Sensory Abnormalities of Children and Adults with Autism. *J Autism Dev Disord*. 2006Mar;37(5):894–910.
10. Stein LI, Lane CJ, Williams ME, Dawson ME, Polido JC, Cermak SA. Physiological and Behavioral Stress and Anxiety in Children with Autism Spectrum Disorders during Routine Oral Care. *BioMed Research International*. 2014;2014:1–10.

11. Brickhouse TH, Farrington FH, Best AM, Ellsworth CW. Barriers to dental care for children in Virginia with autism spectrum disorders [Internet]. *J Dent Child* (Chicago, Ill.). U.S. National Library of Medicine; 2009. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/19941759>
12. Wiener RC, Vohra R, Sambamoorthi U, Madhavan SS. Caregiver Burdens and Preventive Dental Care for Children with Autism Spectrum Disorder, Developmental Disability and/or Mental Health Conditions: National Survey of CSHCN, 2009–2010. *Matern. Child Health J.* 2016;20(12):2573–80.
13. Orellana LM, Martínez-Sanchis S, Silvestre FJ. Training Adults and Children with an Autism Spectrum Disorder to be Compliant with a Clinical Dental Assessment Using a TEACCH-Based Approach. *J Autism Dev Disord.* 2013Apr;44(4):776–85.
14. Mintz J, Branch C, March C, Lerman S. Key factors mediating the use of a mobile technology tool designed to develop social and life skills in children with Autistic Spectrum Disorders. *Comput Educ.* 2012;58(1):53–62.
15. Mintz J. Additional key factors mediating the use of a mobile technology tool designed to develop social and life skills in children with Autism Spectrum Disorders: Evaluation of the 2nd HANDS prototype. *Comput Educ.* 2013;63:17–27.
16. Nicolás FT. Tecnologías de Ayuda en Personas con Trastornos del Espectro Autista: Guía Para Docentes [Internet]. 2004. Available from: <http://diversidad.murciaeduca.es/tecnoneet/docs/autismo.pdf>
17. Ploog BO, Scharf A, Nelson D, Brooks PJ. Use of Computer-Assisted Technologies (CAT) to Enhance Social, Communicative, and Language Development in Children with Autism Spectrum Disorders. *J Autism Dev Disord.* 2012;43(2):301–22.

18. Aresti-Bartolome N, Garcia-Zapirain B. Technologies as Support Tools for Persons with Autistic Spectrum Disorder: A Systematic Review. *Int. J. Environ. Res. Public Health*. 2014Apr;11(8):7767–802.
19. Takeo T, Toshitaka N, Daisuke K. Development application softwares on PDA for autistic disorder children. *IPSJ SIG Tech Rep*. 2007;12:31–8.
20. Kandalaft MR, Didehbani N, Krawczyk DC, Allen TT, Chapman SB. Virtual reality social cognition training for young adults with high-functioning autism. *J Autism Dev Disord*. 2013;43:34–44.
21. Elhorst J, Kooijman R. Barriers in oral hygiene in children with an autism spectrum disorder of various cultural backgrounds in the Netherlands. A qualitative study among special dental care providers [Internet]. Research Gate. 2016. Available from: <https://www.researchgate.net/publication/307938624>
22. Marshall J, Sheller B, Mancl L. Caries-risk assessment and caries status of children with autism [Internet]. *Pediatr Dent*. U.S. National Library of Medicine; 2010 [cited 2019Sep29]. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/20298657>
23. Autism Spectrum Disorder [Internet]. National Institute of Mental Health. U.S. Department of Health and Human Services; Available from: <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>
24. Jhangiani R, Tarry H, Stangor C. Principles of social psychology. Vancouver: BCcampus OpenEd; 2014.
25. Cermak SA, Duker LIS, Williams ME, Dawson ME, Lane CJ, Polido JC. Sensory Adapted Dental Environments to Enhance Oral Care for Children with Autism Spectrum

- Disorders: A Randomized Controlled Pilot Study. *J Autism Dev Disord*. 2015Jan;45(9):2876–88.
26. Veerkamp JSJ. 3: Children's Behavior in the Dental Office [Internet]. Pocket Dentistry. 2015. Available from: <https://pocketdentistry.com/3-childrens-behavior-in-the-dental-office/>
27. Vaillant AAJ, Zito PM. Immediate Hypersensitivity Reactions [Internet]. Europe PMC. StatPearls Publishing; 2019. Available from: <https://europepmc.org/books/NBK513315;jsessionid=03A27D828DF756F37181D33748B6D728>
28. Armfield JM. How do we measure dental fear and what are we measuring anyway? *Oral Health Prev Dent*. 2010;8(2):107–15.
29. Appukuttan D. Strategies to manage patients with dental anxiety and dental phobia: literature review. *Clin Cosmet Investig Dent*. 2016;35.
30. Oral health [Internet]. World Health Organization. World Health Organization; 2019. Available from: https://www.who.int/oral_health/en/
31. Gupta B, Johnson3 NW. Evidence of past dental visits and incidence of head and neck cancers: a systematic review and meta-analysis [Internet]. *Syst Rev*. BioMed Central; 2019. Available from: <https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/s13643-019-0949-0>
32. Becker DE, Reed KL. Local Anesthetics: Review of Pharmacological Considerations. *Anesth Prog*. 2012;59(2):90–102.
33. Forman SA, Chin VA. General Anesthetics and Molecular Mechanisms of Unconsciousness. *Int Anesthesiol Clin*. 2008;46(3):43–53.

34. Tobias J, Leder M. Procedural sedation: A review of sedative agents, monitoring, and management of complications. *Saudi J Anaesth*. 2011;5(4):395–410.
35. Garla B, Satish G, Divya K. Dental insurance: A systematic review. *J Int Soc Prev Community Dent*. 2014;4(5):73–77.
36. Adamsen C, Schroeder S, Lemire S, Carter P. Education, Income, and Employment and Prevalence of Chronic Disease Among American Indian/Alaska Native Elders. *Prev Chronic Dis*. 2018;15.
37. Dental crisis in America: The need to expand access. [cited 2015Jul15]; Available from: <http://www.sanders.senate.gov/imo/media/doc/DENTALCRISIS.REPORT.pdf>
38. Boat TF. Prevalence of Autism Spectrum Disorder [Internet]. Mental Disorders and Disabilities Among Low-Income Children. U.S. National Library of Medicine; 2015 [cited 2018Oct7]. Available from: https://www.ncbi.nlm.nih.gov/books/NBK332896#ref_000438
39. Community Report on Autism 2018 [Internet]. CDC. Autism and Developmental Disabilities Monitoring Network; 2018. Available from: Autism and Developmental Disabilities Monitoring Network
40. Zablotsky B, Black LI, Maenner MJ, Schieve LA, Blumberg SJ. Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey. *Natl Health Stat Report*. 2015Nov13;87:1–20.
41. Identification of children with disabilities [Internet]. Virginia Department of Education. [cited 2018Oct7]. Available from: <https://www2.ed.gov/fund/data/report/idea/partbspap/2013/va-acc-stateprofile-11-12.pdf>


42. Mckinney CM, Nelson T, Scott JM, Heaton LJ, Vaughn MG, Lewis CW. Predictors of Unmet Dental Need in Children With Autism Spectrum Disorder: Results From a National Sample. *Acad Pediatr*. 2014;14(6):624–31.
43. Rai K, Hegde AM, Jose N. Salivary antioxidants and oral health in children with autism. *Arch Oral Biol*. 2012;57(8):1116–20.
44. Fahlvik-Planefeldt C, Herrstrom P. Dental care of autistic children within the nonspecialized Public Dental Service. *Swed Dent J*. 2001;25:113–8.
45. Shapira J, Mann J, Tamari I, Mester R, Knobler H, Yoeli Y, et al. Oral health status and dental needs of an autistic population of children and young adults. *Spec Care Dentist*. 1989;9(2):38–41.
46. Periodontal status and orthodontic treatment need of autistic children. *J World Fed Orthod*. 11(3):256–61.
47. DeMattei R, Cuvo A, Maurizio S. Oral Assessment of Children with an Autism Spectrum Disorder. *J Dent Hyg*. 2007Jul;18(3):1–11.
48. Chandrashekhar S, Bommangoudar JS. Management of Autistic Patients in Dental Office: A Clinical Update. *Int J Clin Pediatr Dent*. 2018;11(3):219–27.
49. Fontaine-Sylvestre C, Roy A, Rizkallah J, Dabbagh B, Santos BFD. Prevalence of malocclusion in Canadian children with autism spectrum disorder. *Am J Orthod Dentofacial Orthop*. 2017;152(1):38–41.
50. Vohra R, Madhavan S, Sambamoorthi U, Peter CS. Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*. 2013;18(7):815–26.

51. Khatib AAE, Tekeya MME, Tantawi MAE, Omar T. Oral health status and behaviours of children with Autism Spectrum Disorder: a case-control study. *Int J Paediatr Dent*. 2013;24(4):314–23.
52. Stein LD, Polido J, Najera S, Cermak S. Oral Care Experiences and Challenges Children with Autism Spectrum Disorders. *Pediatr. Dent*. 2012;34:387–91.
53. Newschaffer CJ, Curran LK. Autism: an emerging public health problem. *Public Health Rep*. 2003;118(5):393–9.
54. Bultas MW, Mcmillin SE, Zand DH. Reducing Barriers to Care in the Office-Based Health Care Setting for Children With Autism. *J Pediatr Health Care*. 2016;30(1):5–14.
55. Kerns CM, Kendall PC, Berry L, Souders MC, Franklin ME, Schultz RT, et al. Traditional and Atypical Presentations of Anxiety in Youth with Autism Spectrum Disorder. *J Autism Dev Disord*. 2014Jun;44(11):2851–61.
56. Ellmore JL, Bruhn AM, Bobzein JL. Interventions for the reduction of dental anxiety and corresponding behavioral deficits in children with autism spectrum disorder . *J Dent Hyg*. 2016;90(2):93–103.
57. Stein LI, Polido JC, Mailloux Z, Coleman GG, Cermak SA. Oral care and sensory sensitivities in children with autism spectrum disorders. *Spec Care Dentist*. 2011;31(3):102–10.
58. Balakas K, Gallaher CS, Tilley C. Optimizing Perioperative Care for Children and Adolescents with Challenging Behaviors. *MCN Am J Matern Child Nurs*. 2015;40(3):153–9.
59. Jindal R, Karda B. Autistic Child - Does Management Differ? *Int J Contemp Dent*. 2011;2(4):31–4.

60. Lee J, Takehashi H, Nagai C, Obinata G, Stefanov D. Which Robot Features Can Stimulate Better Responses from Children with Autism in Robot-Assisted Therapy? *Int J Adv Robot Syst.* 2012;9(3):72.
61. Nunn J. Behavior Management - Children and Adolescents. *Disability and Oral Care.* 2000:82–92.
62. Shapiro M, Sgan-Cohen HD, Parush S, Melmed RN. Influence of Adapted Environment on the Anxiety of Medically Treated Children with Developmental Disability. *J Pediatr.* 2009;154(4):546–50.
63. Eades D, Leung P, Cronin A, Monteiro J, Johnson A, Remington A. UK dental professionals knowledge, experience and confidence when treating patients on the autism spectrum. *Br Dent J.* 2019;227(6):504–10.
64. Hernandez P, Ikkanda Z. Applied behavior analysis: behavior management of children with autism spectrum disorders in dental environments. *J Am Dent Assoc.* 2011Mar;142(3):281–7.
65. Agili DEA, Roseman J, Pass MA, Thornton JB, Chavers LS. Access to dental care in Alabama for children with special needs. *J Am Dent Assoc.* 2004;135(4):490–5.

APPENDIX A

SURVEY TOOL



OLD DOMINION
UNIVERSITY
I D E A F U S I O N

Dental Access Survey

For
Children with Autism Spectrum Disorders

This survey concerns children with **Autism Spectrum Disorders (ASD)**. Children with ASD include those with a documented medical diagnosis of Pervasive Developmental Disorders (PDD), Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorders Not- Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder, or Rett's Disorder.

Q1. Do you have one or more children with ASD between the ages of 3-17?

- Yes, one child with ASD who is between the ages of 3-17.
- Yes, more than one child with ASD between the ages of 3-17 (Please answer the survey referring to the child with ASD who visited the dentist MOST RECENTLY. If no children with ASD have visited the dentist, please answer the survey referring to the oldest child with ASD).
- No, I do not have a child with ASD (please stop here and return the survey).
- Do not know/not sure if I have a child with ASD (please stop here and return the survey).
- Yes, one or more children with ASD, but the age(s) is less than 3-years or more than 17-years (please stop here and return the survey).

Q2. Gender of Child:

- Male
- Female

Q3. Age of the child:

Q4. What is your child's race? (check all that apply)

- White
- African American
- American Indian or Alaska Native
- Asian
- Other

Q5.

What is your relationship to the child in question? (please check one)

- Parent
- Stepparent
- Legal guardian
- Other (please list):

Q6. What is your current employment status? (please check one)

- Employed full-time
- Employed part-time
- Unemployed looking for work
- Retired
- Homemaker
- Student
- Other (please list):

Q7. Including all sources of income, please indicate your approximate household gross income in 2018:

- Less than \$10,000
- \$10,000-\$19,999
- \$20,000-\$34,999
- \$35,000-\$49,999
- \$50,000-\$74,999
- \$75,000-\$99,999
- \$100,000 or more

Q8. Does your child have dental insurance?

- Yes
- No

Q9.

How often does your child brush his/her teeth with or without assistance? (please check one)

- More than once a day
- Once a day
- 2-6 times a week
- Once a week or less frequently
- Do not know

Q10. How often does your child require assistance to brush his/her teeth? (please check one)

- Always
- Most of the time
- Some of the time
- Rarely
- Never

Q11. Is it difficult for you to brush, or assist in brushing your child's teeth?

- Yes (continue to question 12)
- No (skip to question 13)

Q12.

How difficult is it for you to brush, or assist in brushing your child's teeth? (please check one)

- Unable to brush child's teeth
- Very difficult
- Somewhat difficult
- Somewhat easy
- Easy

Q13. Does your child have a dentist for periodic oral health care (ex: examinations, preventive procedures, routine treatment)?

- Yes
- No

Q14.

Please indicate the last time your child received dental care from a dentist or dental hygienist.

- Within the last 6 months
- 6+ months to 1 year ago
- 1+ to 2 years ago
- 2+ to 4 years ago
- Over 4+ years ago
- Do not know
- Has never received dental care (skip to question 27)

Q15.

Is your child currently scheduled for a dental checkup sometime within the next 6 months?

- Yes (skip to question 17)
- No (continue with question 16)

Q16. Please indicate the reason(s) why your child is not currently scheduled for a dental checkup sometime within the next 6 months (check all that apply).

- I cannot find a dentist with special skill or willingness to work with people having disabilities (i.e., ASD)
- There are no dental services available in my area of the state
- My child's health insurance does not cover dental services
- I cannot find a dentist who participates in the Medicaid Waiver Program
- I cannot get transportation to the dental office
- Other reason (please specify):

Q17. How much time did it take you to travel to your child's most recent dental visit?

- Less than 30 minutes
- Between 30 minutes to 1 hour
- Between 1 and 2 hours
- More than 2 hours

Q18. Approximately how long was your child's last dental cleaning and/or checkup, not including waiting time or time needed to check out?

- 1-30 minutes
- 31-60 minutes
- 61-90 minutes
- More than 90 minutes

Q19.

In what settings are dental procedures for your child usually performed? (please check all that apply)

| | Dental office | Hospital | Other |
|---|--------------------------|--------------------------|--------------------------|
| A. Cleanings and Checkups | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| B. Treatments (Fillings, Crowns, Extractions, Dentures, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Q20. Please select the best description of your child's past behavior as a patient in the dental office:

| | Cooperative | Somewhat uncooperative | Extremely uncooperative |
|---|--------------------------------------|----------------------------------|--|
| A. Cooperation in dental setting | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| B. Fear of Dentist and/or Dental Assistants | Not fearful <input type="radio"/> | Fearful <input type="radio"/> | Excessively Fearful <input type="radio"/> |

Q21. If required, what type of anesthesia does your child require before or during dental visits?

- No anesthesia required.
- Requires only local anesthetic, sometimes enhanced by a sedative taken prior to the appointment.
- May require some form of oral medication to make child sleepy.
- Requires general anesthesia (having child put to sleep) due to being extremely uncooperative.

Q22.

Has your child ever received any intervention for the reduction of dental anxiety and/or corresponding behavioral issues before or during dental visits?

- Yes (continue with question 23)
- No (skip to question 25)

Q23.

Which intervention was used? (Check all that apply)

- Picture cards (such as PECS, social stories, and social cue cards)
- Video technologies (such as video peer modeling, video goggles, and animated video)
- Mobile applications (such as multiple iPad applications and cognitive support application for smartphones)
- Other (please specify):

Q24.

In your opinion, was using the intervention helpful to your child?

- No
- Yes (please explain):

Q25.

Has a dentist or dental office ever refused to treat your child?

- Yes (continue with question 26)
- No (skip to question 29)

Q26.

Did the dentist or dental office who refused to treat your child provide an explanation?

- Yes (continue with question 27)
- No (skip to question 28)

Q27. What was the explanation given for refusal of treatment? (Check all that apply)

- Currently not accepting new patients
- Medicaid Waiver Program not accepted
- Dentist not trained/comfortable treating patients with autism spectrum disorders
- Dental office not properly equipped to care for patients with autism spectrum disorders
- Other

Q28. In your opinion, other than the reasons listed above, were there other factors that may have influenced the dentist or dental office's willingness to treat your child?

- No
- Yes (please explain):

Q29. In your opinion, does having ASD pose a barrier to your child receiving dental care

- No
- Yes (please explain):

Q30.

In your opinion, does your child have any additional mental and/or physical conditions that pose a barrier to your child receiving dental care?

No

Yes (please explain):

APPENDIX B
SURVEY RESULTS

Survey responses of 57 participants who completed the survey.

Q2 What is your child's gender?

| Q2 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---------------|------------------|----------------|---------------------------------|-------------------------------|
| Female | 12 | 21.05 | 12 | 21.05 |
| Male | 45 | 78.95 | 57 | 100.00 |

Q4 What is your child's race? (check all that apply)

| Q4 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|-------------------------|------------------|----------------|---------------------------------|-------------------------------|
| African American | 10 | 18.18 | 10 | 18.18 |
| Mixed Race | 6 | 10.91 | 16 | 29.09 |
| Other | 3 | 5.45 | 19 | 34.55 |
| White | 36 | 65.45 | 55 | 100.00 |

Frequency Missing = 2

Q5 What is your relationship to the child in question? (please check one)

| Q5 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|-----------------------|------------------|----------------|---------------------------------|-------------------------------|
| Legal guardian | 6 | 10.53 | 6 | 10.53 |
| Parent | 51 | 89.47 | 57 | 100.00 |

Q6 What is your current employment status? (please check one)

| Q6 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---------------------------|------------------|----------------|---------------------------------|-------------------------------|
| Employed full-time | 29 | 50.88 | 29 | 50.88 |

| Q6 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---------------------------|------------------|----------------|---------------------------------|-------------------------------|
| Employed part-time | 7 | 12.28 | 36 | 63.16 |
| Homemaker | 14 | 24.56 | 50 | 87.72 |
| Other | 1 | 1.75 | 51 | 89.47 |
| Retired | 5 | 8.77 | 56 | 98.25 |
| Student | 1 | 1.75 | 57 | 100.00 |

Q7 Including all sources of income, please indicate your approximate household gross income in 2018:

| Q7 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|--------------------------|------------------|----------------|---------------------------------|-------------------------------|
| \$100,000 or more | 16 | 31.37 | 16 | 31.37 |
| \$20,000-\$34,999 | 8 | 15.69 | 24 | 47.06 |
| \$35,000-\$49,999 | 5 | 9.80 | 29 | 56.86 |
| \$50,000-\$74,999 | 10 | 19.61 | 39 | 76.47 |
| \$75,000-\$99,999 | 12 | 23.53 | 51 | 100.00 |

Frequency Missing = 6

Q8 Does your child have dental insurance?

| Q8 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|------------|------------------|----------------|---------------------------------|-------------------------------|
| No | 4 | 7.02 | 4 | 7.02 |
| Yes | 53 | 92.98 | 57 | 100.00 |

Q9 How often does your child brush his/her teeth with or without assistance? (please check one)

| Q9 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|-------------------------|------------------|----------------|---------------------------------|-------------------------------|
| 2-6 times a week | 3 | 5.26 | 3 | 5.26 |
| Do not know | 1 | 1.75 | 4 | 7.02 |

| Q9 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---------------------------------------|------------------|----------------|---------------------------------|-------------------------------|
| More than once a day | 28 | 49.12 | 32 | 56.14 |
| Once a day | 20 | 35.09 | 52 | 91.23 |
| Once a week or less frequently | 5 | 8.77 | 57 | 100.00 |

Q10 How often does your child require assistance to brush his/her teeth? (please check one)

| Q10 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|-------------------------|------------------|----------------|---------------------------------|-------------------------------|
| Always | 13 | 22.81 | 13 | 22.81 |
| Most of the time | 12 | 21.05 | 25 | 43.86 |
| Never | 7 | 12.28 | 32 | 56.14 |
| Rarely | 11 | 19.30 | 43 | 75.44 |
| Some of the time | 14 | 24.56 | 57 | 100.00 |

Q11 Is it difficult for you to brush, or assist in brushing your child's teeth?

| Q11 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|--------------------------------------|------------------|----------------|---------------------------------|-------------------------------|
| No (skip to question 13) | 35 | 62.50 | 35 | 62.50 |
| Yes (continue to question 12) | 21 | 37.50 | 56 | 100.00 |

Frequency Missing = 1

Q12 How difficult is it for you to brush, or assist in brushing your child's teeth? (please check one)

| Q12 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---------------------------|------------------|----------------|---------------------------------|-------------------------------|
| Easy | 1 | 4.00 | 1 | 4.00 |
| Somewhat difficult | 15 | 60.00 | 16 | 64.00 |
| Somewhat easy | 4 | 16.00 | 20 | 80.00 |

| Q12 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|-----------------------|------------------|----------------|---------------------------------|-------------------------------|
| Very difficult | 5 | 20.00 | 25 | 100.00 |

Frequency Missing = 32

Q13 Does your child have a dentist for periodic oral health care (ex: examinations, preventive procedures, routine treatment)?

| Q13 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|------------|------------------|----------------|---------------------------------|-------------------------------|
| No | 6 | 11.11 | 6 | 11.11 |
| Yes | 48 | 88.89 | 54 | 100.00 |

Q14 Please indicate the last time your child received dental care from a dentist or dental hygienist.

Frequency Missing = 3

| Q14 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---------------------------------|------------------|----------------|---------------------------------|-------------------------------|
| 1+ to 2 years ago | 3 | 5.26 | 3 | 5.26 |
| 2+ to 4 years ago | 2 | 3.51 | 5 | 8.77 |
| 6+ months to 1 year ago | 10 | 17.54 | 15 | 26.32 |
| Within the last 6 months | 42 | 73.68 | 57 | 100.00 |

Q15 Is your child currently scheduled for a dental checkup sometime within the next 6 months?

| Q15 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---------------------------------------|------------------|----------------|---------------------------------|-------------------------------|
| No (continue with question 16) | 8 | 14.04 | 8 | 14.04 |
| Yes (skip to question 17) | 49 | 85.96 | 57 | 100.00 |

Q16 Please indicate the reason(s) why your child is not currently scheduled for a dental checkup sometime within the next 6 months (check all that apply).

| Q16 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---|------------------|----------------|-----------------------------|---------------------------|
| I cannot find a dentist with special skill or willingness to work with people having disabilities (i.e., ASD) | 3 | 37.50 | 3 | 37.50 |
| My child's health insurance does not cover dental services | 1 | 12.50 | 4 | 50.00 |
| My child's health insurance does not cover dental services,I cannot find a dentist who participates in the Medicaid Waiver Program | 1 | 12.50 | 5 | 62.50 |
| Other reason | 3 | 37.50 | 8 | 100.00 |

Frequency Missing = 49

Q17 How much time did it take you to travel to your child's most recent dental visit?

| Q17 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|-------------------------------------|------------------|----------------|-----------------------------|---------------------------|
| Between 1 and 2 hours | 1 | 1.79 | 1 | 1.79 |
| Between 30 minutes to 1 hour | 14 | 25.00 | 15 | 26.79 |
| Less than 30 minutes | 41 | 73.21 | 56 | 100.00 |

Frequency Missing = 1

Q18 Approximately how long was your child's last dental cleaning and/or checkup, not including waiting time or time needed to check out?

| Q18 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|----------------------|------------------|----------------|-----------------------------|---------------------------|
| 1-30 minutes | 26 | 45.61 | 26 | 45.61 |
| 31-60 minutes | 25 | 43.86 | 51 | 89.47 |
| 61-90 minutes | 6 | 10.53 | 57 | 100.00 |

Q19 In what settings are dental procedures for your child usually performed? (please check all that apply)

A. Cleanings and Checkups:

| Q19_A | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|----------------------|------------------|----------------|---------------------------------|-------------------------------|
| Dental office | 55 | 96.49 | 55 | 96.49 |
| Hospital | 2 | 3.51 | 57 | 100.00 |

Q19 In what settings are dental procedures for your child usually performed? (please check all that apply)

B. Treatments (Fillings, Crowns, Extractions, Dentures, etc.):

| Q19_B | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|----------------------|------------------|----------------|---------------------------------|-------------------------------|
| Dental office | 28 | 68.29 | 28 | 68.29 |
| Hospital | 11 | 26.83 | 39 | 95.12 |
| Other | 2 | 4.88 | 41 | 100.00 |

Frequency Missing = 16

Q20 Please select the best description of your child's past behavior as a patient in the dental office:

A. Cooperative:

| Q20_A | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|--------------------------------|------------------|----------------|---------------------------------|-------------------------------|
| Cooperative | 23 | 41.07 | 23 | 41.07 |
| Extremely uncooperative | 11 | 19.64 | 34 | 60.71 |
| Somewhat uncooperative | 22 | 39.29 | 56 | 100.00 |

Frequency Missing = 1

Q20 Please select the best description of your child's past behavior as a patient in the dental office:

B. Fearful:

| Q20_B | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|----------------------------|------------------|----------------|---------------------------------|-------------------------------|
| Excessively Fearful | 9 | 16.67 | 9 | 16.67 |
| Fearful | 25 | 46.30 | 34 | 62.96 |
| Not fearful | 20 | 37.04 | 54 | 100.00 |

Frequency Missing = 3

Q21 If required, what type of anesthesia does your child require before or during dental visits?

| Q21 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---|------------------|----------------|---------------------------------|-------------------------------|
| May require some form of oral medication to make child sleepy. | 10 | 17.54 | 10 | 17.54 |
| No anesthesia required. | 34 | 59.65 | 44 | 77.19 |
| Requires general anesthesia (having child put to sleep) due to being extremely uncooperative. | 10 | 17.54 | 54 | 94.74 |
| Requires only local anesthetic, sometimes enhanced by a sedative taken prior to the appointment. | 3 | 5.26 | 57 | 100.00 |

Q22 Has your child ever received any intervention for the reduction of dental anxiety and/or corresponding behavioral issues before or during dental visits?

| Q22 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|--|------------------|----------------|---------------------------------|-------------------------------|
| No (skip to question 25) | 34 | 59.65 | 34 | 59.65 |
| Yes (continue with question 23) | 23 | 40.35 | 57 | 100.00 |

Q23 Which intervention was used? (Check all that apply)

| Q23 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---|------------------|----------------|---------------------------------|-------------------------------|
| Mobile applications (such as multiple iPad applications and cognitive support application for smartphones) | 2 | 8.70 | 2 | 8.70 |
| Other (please specify): | 9 | 39.13 | 11 | 47.83 |
| Picture cards (such as PECS, social stories, and social cue cards) | 3 | 13.04 | 14 | 60.87 |
| Picture cards (such as PECS, social stories, and social cue cards), Mobile applications (such as multiple iPad applications and cognitive support application for smartphones) | 1 | 4.35 | 15 | 65.22 |
| Picture cards (such as PECS, social stories, and social cue cards), Other (please specify): | 3 | 13.04 | 18 | 78.26 |
| Picture cards (such as PECS, social stories, and social cue cards), Video technologies (such as video peer modeling, video goggles, and animated video) | 1 | 4.35 | 19 | 82.61 |
| Picture cards (such as PECS, social stories, and social cue cards), Video technologies (such as video peer modeling, video goggles, and animated video), Other (please specify): | 1 | 4.35 | 20 | 86.96 |
| Video technologies (such as video peer modeling, video goggles, and animated video), Mobile applications (such as multiple iPad applications and cognitive support application) | 3 | 13.04 | 23 | 100.00 |

Frequency Missing = 34

Q24 In your opinion, was using the intervention helpful to your child?

| Q24 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|------------|------------------|----------------|---------------------------------|-------------------------------|
| No | 2 | 8.70 | 2 | 8.70 |
| Yes | 21 | 91.30 | 23 | 100.00 |

Frequency Missing = 34

Q25 Has a dentist or dental office ever refused to treat your child?

| Q25 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|--|------------------|----------------|---------------------------------|-------------------------------|
| No (skip to question 29) | 48 | 84.21 | 48 | 84.21 |
| Yes (continue with question 26) | 9 | 15.79 | 57 | 100.00 |

Q26 Did the dentist or dental office who refused to treat your child provide an explanation?

| Q26 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|--|------------------|----------------|---------------------------------|-------------------------------|
| No (skip to question 28) | 6 | 46.15 | 6 | 46.15 |
| Yes (continue with question 27) | 7 | 53.85 | 13 | 100.00 |

Frequency Missing = 44

Q27 What was the explanation given for refusal of treatment? (Check all that apply)

| Q27 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|--|------------------|----------------|---------------------------------|-------------------------------|
| Currently not accepting new patients, Medicaid Waiver Program not accepted, Dentist not trained/comfortable treating patients with autism spectrum disorders, Dental office not properly equipped to care for patients with autism spectrum disorders | 1 | 12.50 | 1 | 12.50 |

| Q27 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---|------------------|----------------|---------------------------------|-------------------------------|
| Dental office not properly equipped to care for patients with autism spectrum disorders | 1 | 12.50 | 2 | 25.00 |
| Dentist not trained/comfortable treating patients with autism spectrum disorders | 1 | 12.50 | 3 | 37.50 |
| Dentist not trained/comfortable treating patients with autism spectrum disorders, Dental office not properly equipped to care for patients with autism spectrum disorders | 2 | 25.00 | 5 | 62.50 |
| Dentist not trained/comfortable treating patients with autism spectrum disorders, Dental office not properly equipped to care for patients with autism spectrum disorders, Other | 1 | 12.50 | 6 | 75.00 |
| Medicaid Waiver Program not accepted, Dentist not trained/comfortable treating patients with autism spectrum disorders | 1 | 12.50 | 7 | 87.50 |
| Other | 1 | 12.50 | 8 | 100.00 |

Frequency Missing = 49

Q28 In your opinion, other than the reasons listed above, were there other factors that may have influenced the dentist or dental office's willingness to treat your child?

| Q28 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|------------|------------------|----------------|---------------------------------|-------------------------------|
| No | 8 | 57.14 | 8 | 57.14 |
| Yes | 6 | 42.86 | 14 | 100.00 |

Frequency Missing = 43

Q29 In your opinion, does having ASD pose a barrier to your child receiving dental care?

| Q29 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|------------|------------------|----------------|---------------------------------|-------------------------------|
| No | 17 | 30.36 | 17 | 30.36 |
| Yes | 39 | 69.64 | 56 | 100.00 |

Frequency Missing = 1

Q30 In your opinion, does your child have any additional mental and/or physical conditions that pose a barrier to your child receiving dental care?

| Q30 | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|------------|------------------|----------------|---------------------------------|-------------------------------|
| No | 43 | 75.44 | 43 | 75.44 |
| Yes | 14 | 24.56 | 57 | 100.00 |

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EDUCATION:

Old Dominion University 2019
 Master of Science in Dental Hygiene

Albaha University 2014
 Saudi Arabia
 Bachelor of Science in Dental Hygiene

EXPERIENCE:**Academic Appointments**

2015-2016 Dental Hygienist-delivered lectures in more than 30 schools in various cities; instructed in and lead application of fluoride substance on special needs students; Participated in Gulf Week for dental health

Internships

2014-2015 Bishah Hospital, Saudi Arabia, Dental Hygiene Internship

HONORS, AWARDS AND PRIZES:

Graduated as first rank with excellent honors

2015 Albaha Region Prince's Prize for Creativity and Scientific Superiority

PROFESSIONAL SERVICE:

2015-2016 Dental Hygienist- Saudi Arabian Ministry of Health

COMMUNITY SERVICE:

2014 Fluoride for disabled children in Al Madinah, Saudi Arabia

2016 Applied fluoride and sealants for primary school students in Al Madinah, Saudi Arabia

TRAINING SEMINARS

2014 Seminar in Dental Health at Bishah Hospital, Bishah, Saudi Arabia

2015 Seminar in Dental Nerves at Bishah Hospital, Bishah, Saudi Arabia

2015 CPR/ Cardiovascular Relief Training at Bishah Hospital, Bishah, Saudi Arabia