Barriers to Dental Care for Children with Autism Spectrum Disorders

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Barriers to Dental Care for Children with Autism Spectrum Disorder

Nidhi Taneja

B.D.S., KLE University, Belgaum, India, 2011

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A Thesis

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Master of Science

At the

University of Connecticut

2018
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Nidhi Taneja

2018
APPROVAL PAGE

Master of Science Thesis
Barriers to Dental Care for Children with Autism Spectrum Disorder

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Mina Mina, D.D.S., Ph.D. Associate Advisor

University of Connecticut
2018
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# NOMENCLATURE

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
</tr>
<tr>
<td>PDD-NOS</td>
<td>Pervasive developmental disorder – not otherwise specified</td>
</tr>
<tr>
<td>CDD</td>
<td>Childhood Disintegrative Disorder</td>
</tr>
<tr>
<td>HFA</td>
<td>High Functioning Autism</td>
</tr>
<tr>
<td>DSM</td>
<td>The Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>CSHCN</td>
<td>Children with Special Health Care Needs</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>HSC</td>
<td>Hospital for Special Care</td>
</tr>
<tr>
<td>ABA</td>
<td>Applied Behavior Analysis</td>
</tr>
</tbody>
</table>
CHAPTER I: INTRODUCTION

1.1 What is Autism Spectrum Disorder

Autism spectrum disorders (ASD) is a complex group of disorders of brain development that affects many areas of the life. It is characterized by a wide range of symptoms, including impairments in language, social interactions, stereotyped behaviors and a markedly restricted repertoire of activities. Autism is a spectrum and includes: Autistic disorder (classic autism), Asperger’s disorder (high-functioning autism), pervasive developmental disorder — not otherwise specified (PDD-NOS), Rett’s disorder, and Childhood Disintegrative Disorder (CDD). In psychiatric nomenclature, children with any of these disorders are considered to have an Autism Spectrum Disorder (ASD).

Children with ASD present with various problems depending on where they are on the spectrum. Those with classic autism disorder are on the more severe end of the spectrum than the other subsets, with an earlier onset, i.e., less than three years of age (Christensen et al., 2016). These children display social awkwardness, resist changes and present with unusual stereotypic behaviors and interests. Communication may be affected to different degrees. Comprehension and expression of language range from totally non-verbal to poorly articulated or delayed speech, to well-spoken sentences with an abnormal tinge or echolalia (Rapin & Tuchman, 2008).

Individuals with Asperger’s disorder, also called high functioning autism (HFA), present with milder symptoms. They do not display a significant lag in cognitive development or in language acquisition. They are also capable of acquiring age-appropriate self-help skills and adaptive behaviors, though they still have difficulty with social interactions (Garrido, Garcia-Fernandez, Garcia-Retamero, & Carballo, 2017).
PDD-NOS typically includes those individuals who have some but not all of the characteristics of classic autism, and are less severely affected than those with autistic disorder. This is also referred to as “sub-threshold autism” by some developmental health professionals.

**New Definition of ASD and Characteristics**

Autism Spectrum Disorder was first described by Leo Kanner in 1943 (Kanner, 1943). Since then, the definition of ASD has changed several times, as the knowledge and understanding of this condition have continuously grown. The most recent definition is based on the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, (DSM-5; American Psychiatric Association, 2013).

The DSM-5 criteria for autism spectrum disorders (ASD) includes two important symptoms.

1. Persistent deficits in social communication and interaction, and

2. Restricted, repetitive patterns of behavior, interests, or activities.

There are three levels of complexity noted in DSM-5 that apply to language and social needs, and to the stereotypic, repetitive behaviors:

Level 1 - those who require some support

Level 2 - those who require substantial support in all areas; and

Level 3 - those who require very substantial support.
Prevalence

*National Prevalence:* The prevalence of ASD has been continuously increasing over the past few decades. From a prevalence estimate of 0.04-0.05% in the 1970s, when autism occurred in four to five per 10,000 children, data from the Autism Development and Disability Monitoring (ADDM) Network 2000-2012 indicates that the prevalence of ASD in the US has increased to 1 in 68 children (Christensen et al., 2016). This increase in prevalence may be due to changes in the diagnostic criteria, an increase in awareness of autism, and/or changes in reporting criteria (Hansen, Schendel, & Parner, 2015; Nassar et al., 2009).

*Prevalence in Connecticut:* According to the Autism Feasibility Study Workgroup, estimates of prevalence of ASD in Connecticut are about 1.14% overall. These estimates are derived from sources such as the Department of Developmental Services - Birth to Three Program (1.04%), and children with ASD receiving healthcare services through the Department of Children and Families (DCFS) (3.09%) (Autism Feasibility Study Workgroup, 2013).

1.2 Importance of Oral Health

Dental caries is the most common chronic disease in childhood. In the US, it is estimated that caries is five times as common as asthma and seven times as common as allergic rhinitis (Benjamin, 2010). Dental problems result in an estimated 52 million hours lost from school (Wang, Chou, & Yu, 2013), and many costly emergency room visits and hospital-based medical and surgical treatments (Sheller, Williams, & Lombardi, 1997).

Dental care is medically necessary to prevent and eliminate orofacial disease, infection, and pain, to restore the form and function of the dentition, and to correct facial disfiguration or
dysfunction. Studies have supported the importance of preventive dental visits from a young age (Bhaskar, McGraw, & Divaris, 2014). Lack of good oral health has been associated with various systemic problems which further manifest in the oral cavity (Hollister & Weintraub, 1993; Rhodus, 2005). Oral health has effects on long-term quality of life and social well-being (Gift, Reisine, & Larach, 1992; Heilmann, Tsakos, & Watt, 2015).

Dental caries and periodontal diseases are both preventable yet highly prevalent chronic conditions. Caries is cumulative and can affect individuals across their life, from early childhood to old age. Good oral health is thus an integral part of a person’s wellbeing and should be given due attention.

1.3 Dental Health Status of Children with ASD and Unmet Needs

Among Children with Special Health Care Needs (CSHCN), those with ASD were twice as likely to have unmet needs and less access to important components of healthcare (Kogan et al., 2008). Several studies have noted unmet dental needs in children with autism (Lai, Milano, Roberts, & Hooper, 2012; Marshall, Sheller, & Mancl, 2010; Nelson et al., 2011). This may be due to the presence of complex medical and behavioral issues such as sensory and motor impairments, language deficits, self-injurious behaviors, anxiety, and depression in children with ASD.

Although the current data regarding the prevalence of dental caries in individuals with ASD are unclear, there are other factors that can affect oral health in a child with ASD. While some researchers have found higher caries scores in children with autism as compared to non-ASD controls (Jaber, 2011; Lowe & Lindemann, 1985), some other studies have found a decreased prevalence of caries in ASD children relative to non-ASD children (Altun et al., 2010;
Klein & Nowak, 1999; Loo, Graham, & Hughes, 2008). Patients who have an ASD diagnosis are at a higher risk than typical patients for gingivitis (Jaber, 2011). Studies have also demonstrated poorer oral hygiene for autistic children (Lowe & Lindemann, 1985; Shapira et al., 1989) which may be due to poor manual dexterity of the child, the caretakers’ difficulty in helping provide oral hygiene to the child, or detrimental effects of various medications on the oral health of the child (Jaber, 2011). One study has also argued for the validity of considering autism as an indicator of high caries risk (Marshall et al., 2010).

1.4 Dentistry-Specific Characteristics of ASD Patients

Providing oral care to children with autism requires adaptation of the skills used in dentistry on a daily basis. Most people with mild or moderate forms of autism can be treated successfully in the general practice setting without using extensive equipment or pharmacological intervention. ASD patients may, however, pose specific challenges that need to be attended to in the dental operatory.

1) **Social Interactions and Communication Problems:** One of the core deficits in ASD concerns social interactions. Persons with ASD may have difficulty in forming new relations and have impaired communication skills (Dawson et al., 2004; Mundy, Sigman, Ungerer, & Sherman, 1986). Going to a dentist involves unusual social interactions, exposure to a new environment, and a requirement for cooperative communication, all of which might be overwhelming for children with ASD, leading to dental anxiety and difficulty in the dental office.

2) **Behavior Problems:** Many children with autistic disorders, display maladaptive behaviors such as aggression, inattentiveness, anxiety etc. (Hartley, Sikora, & McCoy,
2008). In addition to negatively impacting their daily activities, these maladaptive behaviors can complicate their interaction in a dental setting. The invasive nature of many dental procedures, like the use of a dental handpiece for dental cleaning and filling, may trigger disruptive and aggressive behavior causing distress for the dentist as well as the patient. These patients may often require advanced behavioral management strategies (e.g., desensitization and frequent visits, general anesthesia, etc.) (Klein & Nowak, 1999; Limeres-Posse, Castano-Novoa, Abeleira-Pazos, & Ramos-Barbosa, 2014).

3) **Oral Aversions/Sensitivities and Altered Sensory Perceptions:** Dental instruments in the mouth, strong overhead light, noise of the dental instruments, etc., may be perceived as unnatural stimuli and evoke disruptive responses, interrupting dental care. Studies have reported that children with ASD are more likely to object to a toothbrush in the mouth compared to children with other disabilities, thus experiencing greater difficulties with care in both home and dental office settings than their typically developing peers (Stein, Polido, Mailloux, Coleman, & Cermak, 2011; Stein, Polido, Najera, & Cermak, 2012). Atypical and unpredictable body movements are sometimes observed in people with autism (Cook, Blakemore, & Press, 2013). This can jeopardize safety as well as the ability of a dentist to deliver oral health care.

4) **Comorbidities:** Some medical conditions such as intellectual disability, seizure disorder, attention deficit hyperactivity disorder (ADHD), Fragile X syndrome, or gastrointestinal problems are known to sometimes coexist in individuals with ASD (Barton & Volkmar, 1998; Charles, 2010; Hagerman et al., 2017; Holingue, Newill, Lee, Pasricha, & Daniele Fallin, 2017; Rapin & Tuchman, 2008). Medications for managing these conditions may
have dental related side-effects such as xerostomia, dysgeusia, and gingival hyperplasia (Friedlander, Yagiela, Paterno, & Mahler, 2006).

1.5 Barriers to Dental Care for Children with ASD

Barriers to accessing health services lead to unmet health needs, delays in receiving appropriate care, inability to get preventive services, preventable hospitalizations, and financial burdens ("Healthy People 2020," 2018). Children with ASD certainly experience barriers to medical care, as well as barriers to dental care, though these are less well reported (Chiri & Warfield, 2012). Barriers to dental care for children, specifically those with ASD, have been reported in some studies (Barry, O'Sullivan, & Toumba, 2014; Brickhouse, Farrington, Best, & Ellsworth, 2009; Lai et al., 2012). The major problem for ASD patients may not be at the level of dental disease, but the obstacles surrounding provision of appropriate dental care, as described earlier. The barriers in this section are described in three categories; those relating to dentists, to caregivers, and to patient-specific factors.

1.5.1 Dental Provider Factors

Studies suggest that, though most general dentists see special needs patients, the numbers of these patients may be limited. The most common reasons for not treating special needs patients were: the level of the patient's disease, the patient's (disruptive) behavior, and the dentist’s lack of sufficient training or experience (Salama, Kebriaei, & Durham, 2011). It has also been noted the principal barrier for most pediatric dentists in helping transition children with special healthcare needs into adult care is the lack of availability of general dentists willing to accept these patients (Nowak, 2002).
Low insurance reimbursement from state insurance has been shown to be a factor for providers to not participate in Medicaid (Logan, Catalanotto, Guo, Marks, & Dharamsi, 2015). Given that most children with ASD are on state insurance, this could be an important barrier to receiving care.

Dentists with experience in dealing with special needs children are shown to make more accommodations to overcome the challenges faced in treating children with ASD (Weil, Bagramian, & Inglehart, 2011). Lack of training in appropriate skills to treat children with special needs is also a barrier to dental and medical care reported in the literature (Casamassimo, Seale, & Ruehs, 2004; Krauss, Gulley, Sciegaj, & Wells, 2003). One study, however, has shown the positive impact on the ability of primary care providers to improve office-based visits for children with autism when given tools to guide them through the visit of an ASD child (Bultas, McMillin, & Zand, 2016). Guidelines and standardized tools to manage children with autism in the dental office are lacking in the dental literature. This absence of guidelines may be another barrier for the dentists. Other barriers as perceived by the practitioners reported in previous studies include lack of motivation of caretakers and lack of experience and training in managing this population (Adyanthaya, Sreelakshmi, Ismail, & Raheema, 2017).

1.5.2 Caregiver Factors

Caregivers play an important role in providing information about the unique dental and oral care needs of their child with ASD (Lewis, Vigo, Novak, & Klein, 2015). Thus, it is important to take into consideration the factors noted by the caregivers in managing care for children with ASD.
Maternal anxiety before a child's dental treatment is significantly associated with the dental fear experienced by the child himself (Karibe, Aoyagi-Naka, & Koda, 2014). Lower caregiver education is associated with greater caregiver burden and less preventive dental care use (Chi, McManus, & Carle, 2014; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Long waiting times, high cost of care, lack of health insurance, stress levels of the family, and parental education were found to be associated with difficulties in accessing treatment services for children with ASD (Liptak et al., 2008; Manning-Courtney, 2007). Similar barriers, such as difficulty in traveling to the appointment, employment issues, and financial and time burdens are reported by caregivers of children with ASD in some other studies (Nelson et al., 2011; Wiener, Vohra, Sambamoorthi, & Madhavan, 2016).

1.5.3 Patient Factors

Medical procedures performed on patients with intellectual disabilities are more time-consuming and require more physical and emotional involvement, both from parents and medical staff (Burtner, Jones, McNeal, & Low, 1990). Uncooperative behavior of the child was the most common barrier to dental care in the ASD group vs. non ASD group in various studies (Barry et al., 2014; Brickhouse et al., 2009; Lai et al., 2012). The ASD-child may display varied pain threshold, sensory atypicalities and tactile hypersensitivity, which may manifest as lack of distress following injury or disproportionate response to non-noxious stimuli, such as certain fabrics, flavors, and smells (Klin, 2006). Such unpredictable responses can greatly complicate dental care.

One of the most important factors in good dental health is a rigorous and regular home care routine in addition to timely dental visits. A child with ASD may be anxious and
hypersensitive to oral interventions due to sensory disturbances (Stein et al., 2011; Stein et al., 2012). This anxiety and avoidant behavior may interfere with proper home care and with the ability to cooperate with a dentist when doing an oral examination.

Several studies have confirmed delays in language development in ASD spectrum disorders to various degrees (Mitchell et al., 2006; Weismer, Lord, & Esler, 2010). The impaired ability to communicate with children with ASD could pose a major barrier to appropriate care during a dental visit.

1.6 Gaps in the Literature

The importance of oral health to an individual’s well-being cannot be overemphasized. It impacts overall health as well as the quality of life of an individual, including those with disabilities. Patients who have an ASD diagnosis do not necessarily differ from other patients as far as their dental presentations and problems. What differs is the flow of these patients through the dental office, and the management techniques that are employed to have a successful visit with regard to behavior management and communication.

It is important to bridge the gap between the expectations and barriers for the dentists and caregivers of children with ASD diagnoses, so as to better accommodate the behavioral and emotional problems of ASD children in the dental office and at home. Recommendations for home care for caregivers and dental management skills in the office for dentists may make it possible to achieve good oral health outcomes in this population.

The review of the literature shows that no dental research has been conducted regarding the ASD population in Connecticut. To our knowledge, only one other study has been done to
document barriers to providing care from a general dentists’ perspective (Weil & Inglehart, 2010). The purpose of this study is to explore the barriers perceived by both caregivers and dentists to providing optimal dental care to children with ASD in Connecticut.
CHAPTER II: CURRENT STUDIES

2.1 General Background of the Current Research

The purpose of the present project is to explore the (1) barriers faced by dental professionals in treating patients with ASD; and (2) barriers that may be faced by caregivers in meeting the dental needs of their children with ASD. Answers to these questions would help us develop an understanding of the gap in expectations and problems faced in providing care for children with autism from the dentist’s and the caregiver’s perspective.

We suspected that many dentists would be reluctant about treating children with ASD due to lack of skills about how to manage such children, and/or low motivation about providing care to this population due to inadequate reimbursement for their time and effort. We also suspected that caregivers of children with ASD may not prioritize dental health due to lack of knowledge of its importance, or other factors such as lack of access to a dental provider for their child.

By surveying both providers and caregivers the present project was intended to provide a clearer understanding of the issues that need to be addressed in both groups to improve the oral health of ASD children. This project thus has potential to be clinically significant. The results aim to expose the gaps in expectations and resource availability for providers and caregivers, thus setting the agenda for education of both caregivers and dentists, and for the development of guidelines and better reimbursement models for dentists.
2.2 Study 1: Dentists’ Perspectives on Barriers to Care for Children with ASD

2.2.1 Specific Aims
To determine the barriers perceived by the dentists to providing care to patients with ASD.

A. It was hypothesized that there would be a self-perceived lack of experience in treating patients with ASD amongst general dentists. Furthermore, it was hypothesized that dentists who do not see patients with ASD will perceive lack of training as a barrier to a greater extent than those who do treat children with ASD.

B. It was hypothesized that the lack of distinct guidelines to manage patients with ASD would also be reported as a barrier to providing care to children with ASD. It was hypothesized that absence of guidelines for care would more likely be endorsed as a barrier to treating ASD patients by dentists who do not treat patients with ASD compared to those who do.

C. It was hypothesized that the lack of insurance reimbursement for recommended practices for children with ASD would be endorsed as a major barrier to treating ASD children for dentists who do not provide care to this population compared to those who do treat ASD patients.

2.2.2 Significance

General dentists see patients of all age groups. They play an important role in delivering care to patients with special needs, especially preventive care and early referral. Since 2013, after the change in the diagnostic definition of ASD, the prevalence of ASD has increased and thus dental practices are seeing more children and adults with this condition. Most of the children with ASD are relatively high-functioning, whose dental needs can be met in a typical dentist’s
office. Given the lack of specialty dentists, the majority of these ASD child patients will have to be seen by the general dentists. Thus, it was important to assess the perspective of general dentists and investigate the barriers to providing care for children with ASD in this group.

2.2.3 Study Design

This was a cross-sectional survey study, conducted at the Yankee Dental Congress at the Boston Convention and Exhibit Center from January 26-29, 2017. Over 7500 dentists, including general dentists and specialists, and 2150 dental students and residents were registered for the conference. We expected to collect 80-100 surveys over the course of four days. The Dental Congress was chosen as the data collection site because it was expected that in-person recruitment of dentists would be more effective than online or mail-in methods. Also, since the conference was not a specialty conference, it would draw dentists from diverse backgrounds and experience in the New England area. We were particularly interested in the reports of general dentists because they would be responsible for the care of ASD patients as children, and especially as the ASD children transition to adult care.

2.2.4 Methods

2.2.4.1 Human Subjects Approval and Consent Form

The study was approved by the Institutional Review Board (IRB) of the University of Connecticut Health Center (UConn). Each dentist was asked to review the consent form outlining the purpose of the study and its procedures before beginning the survey (Appendix 1). Permission was obtained from the UConn Dental Alumni Association to distribute surveys at their booth in the Congress exhibit hall.
### 2.2.4.2 Study participants

A total of 136 completed surveys were collected. Respondents included 102 general dentists, seven general practice dentistry residents, eight pediatric dentists, four endodontists, seven orthodontists, four periodontists, two oral surgeons and two others. General dentists see children in their practice on a regular basis. Our analysis, therefore, was based on 109 general dentists (102 general dentists, seven general practice dentistry residents) only, as this group was considered representative of the population of dentists who would provide care to ASD individuals. Pediatric dentists treat children with ASD as well, but they have two years of advanced education and more experience, and are thus less representative of dentists as a whole. They were not included in the study so as to eliminate any bias owing to their specialized training, motivation, and comfort in treating children. Table 1 shows the characteristics of the dentists in this study, grouped by their self-report of treating children with ASD or not. Most of the dentists who responded to the survey reported treating children with ASD (n=81; 74.3%).
### General Dentist Characteristics

<table>
<thead>
<tr>
<th>Table 1. Characteristics of General Dentists (N=109).</th>
<th>Don't Treat ASD (n=28) (25.7%)</th>
<th>Treat ASD (n=81) (74.3%)</th>
<th>All Dentists (n=109)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dentist Gender</strong> (#, % of sample)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>19 (67.9)</td>
<td>48 (59.3)</td>
<td>67 (61.5)</td>
</tr>
<tr>
<td>Female</td>
<td>9 (32.1)</td>
<td>33 (40.7)</td>
<td>42 (38.5)</td>
</tr>
<tr>
<td><strong>Mean no. of years in Practice (yrs, SD)</strong></td>
<td>13.5 (11.5)</td>
<td>16.3 (12.1)</td>
<td>15.6 (11.95)</td>
</tr>
<tr>
<td><strong>Mean no. of ASD patients seen per month (#, SD)</strong></td>
<td>2.79 (4.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Type of ASD Treated (#, % of sample)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild only</td>
<td>38 (46.9)</td>
<td></td>
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<tr>
<td>Mild-Moderate</td>
<td>36 (44.4)</td>
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<tr>
<td>Mild-Moderate-Severe</td>
<td>7 (8.6)</td>
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<td></td>
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<tr>
<td><strong>Type of Insurance (#, % of sample)</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>1 (4.5)</td>
<td>14 (17.3)</td>
<td>15 (14.6)</td>
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<tr>
<td>Private</td>
<td>12 (54.5)</td>
<td>27 (33.3)</td>
<td>39 (37.9)</td>
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<tr>
<td>Both</td>
<td>9 (40.9)</td>
<td>40 (49.4)</td>
<td>49 (47.6)</td>
</tr>
<tr>
<td><strong>Training source for ASDa (#, % of sample)</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Experience in practice</td>
<td>6 (30)</td>
<td>58 (72.5)</td>
<td>64 (58.7)</td>
</tr>
<tr>
<td>Dental School</td>
<td>9 (45)</td>
<td>22 (27.2)</td>
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<td>22 (27.2)</td>
<td>28 (25.6)</td>
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<td>3 (15)</td>
<td>6 (7.4)</td>
<td>9 (8.3)</td>
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<tr>
<td>Others</td>
<td>3 (15)</td>
<td>4 (4.9)</td>
<td>7 (6.4)</td>
</tr>
</tbody>
</table>

Note: apercentages may exceed 100% due to multiple responses allowed
2.2.4.3 Measures and Instruments: Dentists’ Survey

There were no questionnaires currently in use that address the objectives of this study. Thus, a questionnaire (Appendix 2) was designed and informally piloted among a sample of dentists and caregivers at the Connecticut’s Children’s Medical Center (CCMC). Suggestions made by these respondents were used to modify the questionnaires to address the specific aims of the study.

The final survey instrument administered to the dentists consisted of a single page assessing the following: Demographics, practice type, type of insurance accepted and training received were assessed with six items. Perceived barriers to delivering care to ASD children were assessed with 11 items. Due to the ambiguity of one of these items, 10 items were retained. Barriers surveyed included: Lack of practice guidelines established for the management of a child with ASD, the disruptive behavior of a child with ASD, lack of self-perceived competency to manage a child with ASD, lack of availability of resources, and patients’ special needs. For each potential barrier listed dentists indicated whether they disagreed it was a barrier to providing care (scored -1), were neutral (scored 0), or agreed it was a barrier (scored +1).

2.2.4.4 Procedure

Surveys were available at the University of Connecticut School of Dental Medicine (UConn SDM) Alumni booth, in the exhibit area at Yankee Dental Conference from January 25-29, 2017. Those dentists who came to the booth were asked by a UConn SDM volunteer working at the booth if the dentist conferee would like to complete a short survey on dental care for autistic children. Those who agreed to participate were handed the self-report survey, along with a letter describing the purpose of the survey and emphasizing that any participation was
voluntary. The survey took 3-5 minutes for participants to complete. After the survey was completed participating dentists were instructed to drop the survey in a basket located on a table at the UConn School of Dental Medicine Alumni booth. No compensation was given to the participating dentists. It was expected that about 100 dentists would respond to this invitation and agree to participate. All responding dentists were considered eligible. The data collected through the completed surveys were entered into an SPSS system file for evaluation. No survey respondents were identified individually. Not all respondents answered every question. The missing values were excluded in the denominator for the calculation of percentages.

2.2.4.5 Data Analysis

The dependent variables were two scores derived from the barriers to care items in the survey. The first was the total agreement score calculated by summing the scores of agreement for each of the 10 items (ranging from -10 to +10). The second score was simply the number of barriers that were endorsed as a problem by dentists (ranging from 0 to 10). The independent variables were: dentist’s demographics, dentist’s self-reported experience in treating children with ASD in practice, and type of dental insurance accepted by the dentist’s office. Descriptive analyses included frequencies and percentages for categorical variables, and means and standard deviations for continuous variables. In addition to examining responses from all dentists, the reported barriers were further explored for dentists in two groups: those reporting that they treat children with ASD and those who reported that they did not treat these children. Independent t-tests were used to compare the barrier scores of the two groups of dentists, and chi-square tests were used to compare the two groups of dentists on the various barriers individually.
<table>
<thead>
<tr>
<th>Table 2. Barriers to Providing Care to ASD Children as Perceived by General Dentists. Cell Values Indicate Number of Responses and Percent.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barrier</strong> (&lt; #, % of sample)</td>
</tr>
<tr>
<td><strong>Disagree</strong></td>
</tr>
<tr>
<td>Do not get ASD patients in practice</td>
</tr>
<tr>
<td>ASD children are uncooperative</td>
</tr>
<tr>
<td>I do not have sufficient training</td>
</tr>
<tr>
<td>Lack of practice guidelines</td>
</tr>
<tr>
<td>Lack of sufficient reimbursement for behavior management</td>
</tr>
<tr>
<td>Behavior management/treatment takes too long</td>
</tr>
<tr>
<td>Complex medical problems</td>
</tr>
<tr>
<td>Do not take State insurance</td>
</tr>
<tr>
<td>Caregivers not reliable with appointments</td>
</tr>
<tr>
<td>Office staff not trained</td>
</tr>
<tr>
<td>No. of barriers endorsed (M, SD)</td>
</tr>
<tr>
<td>Total perceived barriers score (M, SD)</td>
</tr>
</tbody>
</table>

Note aChi-square tests of percentages of Non-ASD treating Dentists and ASD-treating Dentists who agree that an item presents a barrier to care.
* p < .05
2.2.5 Results

Table 2 shows the barriers to providing care perceived by the general dentists. On average, the general dentists endorsed 3.25 (SD=2.3) barriers out of 10 for providing care to children with ASD. Their total perceived barrier score was 0.3 on the -10 to 10 scale, suggesting that these general dentists did not perceive these barriers as especially important in their decisions to treat children with ASD.

When subdivided by those who reported treating or not treating ASD children in their practice, the mean number of barriers endorsed by the dentists treating children with ASD was only marginally more than those not treating ASD children and not statistically significant ($t=-0.28; \text{df}=107; p=0.78$). The mean of the total perceived barriers score for the two groups of dentists was significantly higher for those who did not see these children in practice ($t=2.72; \text{df}=107; p=0.0076$).

*Perceived Level of Training*: Less than a quarter of dentists in the present study reported lack of training to be a barrier in treating children with ASD. A significantly higher number of the dentists who do not treat children with ASD felt that insufficient training in treating children with ASD was a barrier to treating this population. Only a quarter of the dentists from both groups felt that the behavioral cooperation of ASD children was a barrier to their treatment, and the result was not statistically significant. Thus, insufficient training was not a major barrier for the dentists in this study and both the groups had a positive attitude toward meeting the behavioral needs of the ASD children.

*Guidelines*: Lack of practice guidelines for treating children with ASD was the most common barrier endorsed by the dentists overall. There was no difference between the two groups. This suggests that establishing clear guidelines for treating ASD children in dental
practice might be beneficial to all dentists and may address one important barrier perceived by general dentists.

*Insurance Reimbursement:* Another common barrier reported by many dentists was the lack of sufficient reimbursement for the behavioral management of ASD children. Interestingly, insurance reimbursement was more likely to be endorsed as a barrier by those who did treat ASD children. Evidently it was not the lack of insurance reimbursement that prevented dentist from treating children with ASD.

Besides the barriers already discussed, there were two other barriers that were significantly different for the two groups of the dentists. More dentists who treat children with ASD felt that the caregivers were not reliable with the appointments. On the other hand, more dentists who did not treat children with ASD said that their office staff was not appropriately trained to see ASD children in their practice.

**2.2.6 Conclusions**

The general dentists in the present study face many barriers in treating children with Autism Spectrum Disorders. The commonly endorsed barriers were the lack of available guidelines, the lack of sufficient reimbursement for behavior management of ASD children, and the difficulty in managing the behavior of a child with ASD. Interestingly, most dentists did not perceive lack of training as a barrier to providing care for these children. Overall, they did not endorse many items as particular barriers to providing care to ASD children.
2.3 Study 2: Caregivers’ Perspectives on Barriers to Dental Care for Children with ASD

2.3.1 Specific Aims
To determine the barriers for caregivers in managing dental care for children with ASD.

A. It was hypothesized that the dental needs of their children would be perceived as a lower priority for the caregivers of children with ASD than for caregivers whose children do not have ASD.

B. It was hypothesized that caregivers of children with ASD would report more barriers to dental care than would caregivers of children without ASD. Furthermore, caregivers of children with more severe forms of autism would report more barriers to dental care than those with children with less severe forms of ASD.

C. It was also hypothesized that one of the major barriers for caregivers of these children would be the inability to find a practice/dentist that can accommodate their children’s behavior management needs, especially those of more severe ASD children.

2.3.2 Significance

Caregivers play an important role in providing home oral care for children with ASD. They are a vital component in efforts to improve oral health outcomes for children with ASD. The home routine of daily brushing and having the child become used to the sensation of a toothbrush in the mouth can both help with sensory behavior adaptation and with maintaining good oral hygiene. The burden on caregivers is high. This burden may constitute a barrier to providing adequate dental care for their children when caregivers are too overwhelmed to attend adequately to oral health. The present study investigates potential barriers to securing care for
ASD children in order to gain a better understanding of their perspective. If barriers can be addressed it may lead to better oral health for children with ASD.

### 2.3.3 Study Design

This was a cross-sectional survey study, conducted at the outpatient Autism clinic at the Hospital for Special Care in New Britain, Connecticut. The study was conducted from December 2016 to June 2017. The clinic sees about 30 children/week with ASD of all age groups who come for various appointments, including diagnosis, occupational therapy, physical therapy, speech therapy, and cognitive and behavioral assessment. For this survey of caregivers we chose a location in an outpatient clinic in the hospital that was not specifically a dental site. We did not want to survey caregivers who already had dental providers associated with the hospital. Additionally, we did not want to include a site with inpatient or institutionalized children with ASD, since they would be on the severe end of the spectrum and would require advanced behavior management in the dental clinic, such as sedation or restraints. The administration of surveys was done in the waiting room at the Autism clinic to minimize the disruption of flow and so as to not interrupt the child’s appointment time. Parents/caregivers waited in the waiting room while their child was in treatment/diagnosis session at the clinic.

### 2.3.4 Method

#### 2.3.4.1 Human Subjects Approval and Consent Form

Approval for the study was obtained from the University of Connecticut, Health Center’s Institutional Review Board (IRB). Each caregiver was asked to review the consent form outlining the purpose of the study and its procedures before beginning the survey (Appendix 2). The project was also approved by the IRB at the Hospital of Special Care.
2.3.4.2 Study Participants

The study consisted of two samples: a sample of caregivers of ASD children, and caregivers of non-ASD children (controls). The ASD caregiver sample for the proposed study was recruited from among those coming to the Autism Center at the Hospital for Special Care (HSC), New Britain, CT. The participants included 46 caregivers of ASD children and 37 caregivers of non-ASD children, who served as controls. The control sample was made up of caregivers of healthy children without an ASD diagnosis, but who were coming to the treatment site for other therapy, such as speech therapy and physical rehabilitation. The purpose of this control group was to determine whether the barriers to dental care perceived by caregivers of ASD children are unique to ASD, or whether they also might apply to other caregivers of non-ASD children.

Caregivers of children with or without a diagnosis of ASD were eligible to participate if they could speak English and if their child was between the ages of 1 and 18 years. ASD diagnosis of those seen in the Autism Center had been established prior to this survey.

2.3.4.3 Measures and Instruments: Caregivers’ Survey

The survey consisted of 33 items assessing the following: Demographics, autism severity, oral hygiene practices, and 10 items tapping potential barriers faced by caregivers in providing dental care for children with ASD. Barriers such as difficulty in finding a dentist familiar with ASD behaviors, lack of insurance, fear of their child acting out, and others, were assessed. The survey was designed for this study and based on similar surveys used in past research (Brickhouse et al., 2009; Lai et al., 2012; Nelson et al., 2011). For each potential barrier listed caregivers indicated their disagreement or agreement that the item constituted a barrier on a 5-point scale scored from -2 to 2.
2.3.4.4 Procedure

A convenience sampling method was employed for the distribution and collection of the surveys. For the study group, all caregivers coming to the site were solicited by the clinic administrative assistants and/or clinic volunteers while they were waiting for their child’s therapy/class. The administrator or volunteer confirmed that the caregiver had not previously participated in the study and that they agreed to participate. The clinic administrator or volunteer handed to the participant a letter describing the purpose of the survey and emphasizing that any participation was voluntary. Each survey took approximately 10 minutes and once completed was placed in a manila envelope and deposited in a tray at the clinic reception desk. Caregivers were not identified. Data collection took place over seven months. Survey respondents were not compensated. The completed surveys were collected every two weeks by the co-investigator, who entered the data collected into an SPSS system file for later analysis.

For the control group (the caregivers of children without ASD diagnosis), the surveys were administered in the same facility using the same procedures as those used for the caregivers of ASD children. The same questionnaire was administered and the first item on the survey distinguished caregivers of children with ASD vs those of healthy controls (i.e., “Does your child have ASD?”).

2.3.4.5 Data Analysis

The data were analyzed and barriers reported by caregivers of children with and without ASD were compared. The ASD caregiver group was subdivided according to the severity of the child’s ASD to get a better understanding of the barriers specific to autism severity. Severity classification was based on the level of self-injurious behavior or aggressiveness, and on
expressive language ability. The children on a milder spectrum would be more typical and would
usually be verbal. Those who showed deficits in language, were non-verbal, or aggressive, were
considered to be more severe on the spectrum. A child under the age of 2 was assumed to be
mildly affected regardless of what parents had reported about their child’s severity, given that an
ASD child under two years is pre-cooperative (a child lacking cooperation ability owing to age
or cognitive ability) and usually not different from a typical two-year-old child at the dentist.
Although classification by verbal behavior and aggressiveness is not considered relevant to ASD
diagnosis per se (Gotham, Pickles, & Lord, 2009), this type of classification is useful in the
context of evaluating suitability for dental treatment in private practice settings.
Severity classifications were defined as follows:

1) Verbal and Non-Aggressive or < 2 y/o = Mild

2) Verbal and Non-Aggressive = Moderate

3) Verbal/Non-Verbal and Aggressive = Severe

The children were also classified into different age groups based on various stages in the child’s
dental development. This was as follows:

1) 1-6 years old - primary dentition

2) 7-13 years old - mixed dentition

3) 14-18 years old - permanent dentition

For the analyses, each of the 10 proposed barrier items was scored on a 5-point Likert-
type scale: Strongly Disagree (scored -2), Disagree (scored -1), Neutral (scored -0), Agree
(scored +1) and Strongly Agree (scored +2). Barriers responses were combined as “disagree” for scores -1 or -2, and as “agreed” for scores +1 or +2. The cumulative barrier score was calculated as the sum of all scores, and ranged from -20 to +20. The total perceived barriers score endorsed was also computed by counting the number of barriers endorsed as “agreed” (i.e., scored as either 1 or 2).

The data were analyzed using descriptive statistics, independent t-tests, and analysis of variance (ANOVA). The independent factors were: child and caregivers’ demographics, child’s oral hygiene habits, oral health status, child’s cooperation level, parents’ perception of child’s oral health, availability of dental insurance and type of dentist seen and others. Descriptive analyses included frequencies and percentages for categorical variables, and means and standard deviations for continuous variables. Chi-square tests were used to compare the individual barriers for the two groups of caregivers.

2.3.5 Results

Responses

A total of 83 caregivers completed surveys. The majority of the caregivers were the parents of children with ASD. Not all respondents answered every question. The missing values were excluded in the denominator for the calculation of percentages. Due to sample size and response distributions across categories, some categorical levels were combined for analysis. These included age of the child, participation in specialized educational services for the child, education level of the caregivers, brushing routine, perceived oral health of the child, importance of oral health, and cooperation level of the child.
Characteristics of Children with and without ASD

Table 3. Characteristics of Autism Spectrum Children and Non-ASD Children (N=83)

<table>
<thead>
<tr>
<th>Child Age (#, % of sample)</th>
<th>Mildly Severe (n=26) (56.5%)</th>
<th>Moderately Severe (n=11) (23.9%)</th>
<th>Severe (n=9) (19.6%)</th>
<th>All ASD</th>
<th>Non-ASD (n=37) (44.6%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-6 yrs</td>
<td>7 (15.2%)</td>
<td>4 (8.7%)</td>
<td>2 (4.3%)</td>
<td>13 (28.3%)</td>
<td>19 (51.4%)</td>
</tr>
<tr>
<td>7-13 yrs</td>
<td>12 (26.1%)</td>
<td>4 (8.7%)</td>
<td>5 (10.9%)</td>
<td>21 (45.7%)</td>
<td>15 (40.5%)</td>
</tr>
<tr>
<td>14-18 yrs</td>
<td>7 (15.2%)</td>
<td>3 (6.5%)</td>
<td>2 (4.3%)</td>
<td>12 (26.1%)</td>
<td>3 (8.1%)</td>
</tr>
</tbody>
</table>

| Mean Age (yrs,SD)         | 9.42 (4.8)                   | 9.27 (4.6)                       | 10.22 (4.5)          | 9.5 (4.6) | 7.2 (4.1)             |

| Specialized Educational Services (IEP) (#, % of sample) | 23 (50) | 10 (21.7) | 7 (15.2) | 40 (86.9) | 7 (18.9) |

<table>
<thead>
<tr>
<th>Type of Insurance (#, % of sample)</th>
<th>None</th>
<th>1 (2.2)</th>
<th>0</th>
<th>1 (2.2)</th>
<th>5 (13.5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public</td>
<td>20 (43.5)</td>
<td>8 (17.4)</td>
<td>8 (17.4)</td>
<td>36 (78.3)</td>
<td>24 (64.9)</td>
</tr>
<tr>
<td>Private</td>
<td>6 (13.04)</td>
<td>2 (4.3)</td>
<td>1 (2.2)</td>
<td>9 (19.6)</td>
<td>8 (21.6)</td>
</tr>
</tbody>
</table>
Table 3 (continued).

<table>
<thead>
<tr>
<th>Type of Dentist seen (#, % of sample)</th>
<th>ASD Children (n=46) (55.4%)</th>
<th>Non-ASD (n=37) (44.6%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Dentist</td>
<td>2 (4.3)</td>
<td>3 (6.5)</td>
</tr>
<tr>
<td>General/CHC</td>
<td>10 (21.7)</td>
<td>16 (34.8)</td>
</tr>
<tr>
<td>Pediatric/Hospital</td>
<td>14 (30.4)</td>
<td>27 (58.7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Frequency of Dental Visits (#, % of sample)</th>
<th>ASD Children (n=46) (55.4%)</th>
<th>Non-ASD (n=37) (44.6%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>3 (6.5)</td>
<td>5 (13.5)</td>
</tr>
<tr>
<td>During pain/SOS</td>
<td>0</td>
<td>4 (8.7)</td>
</tr>
<tr>
<td>Every 6-12 months</td>
<td>23 (50)</td>
<td>28 (75.7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Brushing Frequency (#, % of sample)</th>
<th>ASD Children (n=46) (55.4%)</th>
<th>Non-ASD (n=37) (44.6%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥ 1 time/ day</td>
<td>19 (41.3)</td>
<td>31 (83.8)</td>
</tr>
<tr>
<td>&lt; 1 time/day</td>
<td>7 (15.2%)</td>
<td>6 (16.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expected Level of Cooperation with Dentist (#, % of sample)</th>
<th>ASD Children (n=46) (55.4%)</th>
<th>Non-ASD (n=37) (44.6%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>7 (15.2%)</td>
<td>22 (61.1)</td>
</tr>
<tr>
<td>Good</td>
<td>15 (32.6)</td>
<td>10 (27.8)</td>
</tr>
<tr>
<td>Fair</td>
<td>4 (8.7)</td>
<td>3 (8.3)</td>
</tr>
<tr>
<td>Poor</td>
<td>0</td>
<td>1 (2.8)</td>
</tr>
</tbody>
</table>
Table 3 (continued).

<table>
<thead>
<tr>
<th></th>
<th>ASD Children (n=46) (55.4%)</th>
<th>Non-ASD (n=37) (44.6%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mildly Severe (n=26) (56.5%)</td>
<td>Moderately Severe (n=11) (23.9%)</td>
</tr>
<tr>
<td>Teeth Brushing Routine at Home (#, % of sample)</td>
<td>Uncooperative</td>
<td>2 (4.3)</td>
</tr>
<tr>
<td></td>
<td>Moderately Cooperative</td>
<td>14 (30.4)</td>
</tr>
<tr>
<td></td>
<td>Cooperative</td>
<td>10 (21.7)</td>
</tr>
<tr>
<td>Importance of child's dental health (#, % of sample)</td>
<td>Important (5 or 4)</td>
<td>26 (56.5)</td>
</tr>
<tr>
<td></td>
<td>Somewhat important (3)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Not Important (2 or 1)</td>
<td>0</td>
</tr>
<tr>
<td>Perceived status of child's dental health (#, % of sample)</td>
<td>Excellent</td>
<td>1 (2.2)</td>
</tr>
<tr>
<td></td>
<td>Very Good-Good</td>
<td>20 (43.5)</td>
</tr>
<tr>
<td></td>
<td>Fair - Poor</td>
<td>5 (10.9)</td>
</tr>
<tr>
<td>Caregiver's educational level (#, % of sample)</td>
<td>&lt;= High School Graduate</td>
<td>10 (22.2)</td>
</tr>
<tr>
<td></td>
<td>&gt; High School Graduate</td>
<td>15 (33.3)</td>
</tr>
</tbody>
</table>
Table 3 shows the characteristics of the children of the caregivers in this study grouped by child’s ASD diagnosis and by severity. The majority of the children were verbal and non-aggressive, categorized as mild ASD. Significantly more ASD children were in a special education program at school, an Individualized Education Program (IEP), compared to non-ASD children \( (\chi^2=38.13; \ p=0.0001) \). More children with ASD had co-morbidities such as asthma, ADHD, GI problems etc., than did children without ASD. This was a significant difference \( (\chi^2=9.54; \ p=0.002) \). Some children were receiving additional therapies such as speech and occupational therapy. Almost all the children, regardless of their diagnosis of ASD, had either public or private insurance, but more children without ASD reported being uninsured.

**Barriers to Dental Care for Caregivers of Children with ASD**

Table 4 shows the perceived barriers to dental care for children with ASD from a caregiver’s perspective.
Table 4. Barriers for Caregivers with Autism Spectrum Children and Non-ASD Children (N=83)

<table>
<thead>
<tr>
<th>Barrier to dental care perceived by the caregiver (#, % of sample)</th>
<th>ASD Children (n=46) (55.4%)</th>
<th>Non-ASD (n=37) (44.6%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mildly Severe (n=26)</td>
<td>Moderately Severe (n=11)</td>
</tr>
<tr>
<td>Own fear about dentist</td>
<td>Disagree</td>
<td>22 (84.6)</td>
</tr>
<tr>
<td></td>
<td>Neutral</td>
<td>2 (7.7)</td>
</tr>
<tr>
<td></td>
<td>Agree</td>
<td>2 (7.7)</td>
</tr>
<tr>
<td>Hard to find dentist who takes insurance</td>
<td>Disagree</td>
<td>16 (61.5)</td>
</tr>
<tr>
<td></td>
<td>Neutral</td>
<td>3 (11.5)</td>
</tr>
<tr>
<td></td>
<td>Agree</td>
<td>7 (26.9)</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>Disagree</td>
<td>23 (88.5)</td>
</tr>
<tr>
<td></td>
<td>Neutral</td>
<td>3 (11.5)</td>
</tr>
<tr>
<td></td>
<td>Agree</td>
<td>0</td>
</tr>
<tr>
<td>Child behavior is uncooperative - unpredictable</td>
<td>Disagree</td>
<td>14 (53.8)</td>
</tr>
<tr>
<td></td>
<td>Neutral</td>
<td>4 (15.4)</td>
</tr>
<tr>
<td></td>
<td>Agree</td>
<td>8 (30.8)</td>
</tr>
<tr>
<td>Time constraints</td>
<td>Disagree</td>
<td>17 (65.4)</td>
</tr>
<tr>
<td></td>
<td>Neutral</td>
<td>3 (11.5)</td>
</tr>
<tr>
<td></td>
<td>Agree</td>
<td>6 (23.1)</td>
</tr>
<tr>
<td>Difficult to get an appointment</td>
<td>Disagree</td>
<td>18 (69.2)</td>
</tr>
<tr>
<td></td>
<td>Neutral</td>
<td>6 (23.1)</td>
</tr>
<tr>
<td></td>
<td>Agree</td>
<td>2 (7.7)</td>
</tr>
<tr>
<td>Cannot find dentist comfortable with ASD</td>
<td>Disagree</td>
<td>17 (65.4)</td>
</tr>
<tr>
<td></td>
<td>Neutral</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Agree</td>
<td>9 (34.6)</td>
</tr>
</tbody>
</table>
Perceived Priority of Dental Needs by Caregivers

The majority of caregivers unanimously believed that the dental health of their child was important/very important, and no statistical difference was noted between the two groups ($\chi^2=0.52; p=0.47$). Moreover, most of the children in both groups were seen by a dentist every 6-12 months with no statistical difference by caregiver group ($\chi^2=0.59; p=0.44$). Both these findings suggest that caregivers of children with ASD do not necessarily give lower priority to their child’s dental care than the caregivers with typical children.

<table>
<thead>
<tr>
<th>Barrier to dental care perceived by the caregiver (#, % of sample)</th>
<th>ASD Children (n=46) (55.4%)</th>
<th>Non-ASD (n=37) 44.6%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child is sick with other med problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>23 (88.5)</td>
<td>9 (81.8)</td>
</tr>
<tr>
<td>Neutral</td>
<td>1 (3.8)</td>
<td>1 (9.1)</td>
</tr>
<tr>
<td>Agree</td>
<td>2 (7.7)</td>
<td>1 (9.1)</td>
</tr>
<tr>
<td>Hard to control my child’s behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>16 (61.5)</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Neutral</td>
<td>5 (19.2)</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Agree</td>
<td>5 (19.2)</td>
<td>5 (54.5)</td>
</tr>
<tr>
<td>Difficulty finding care for specialized dental problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>22 (84.6)</td>
<td>9 (81.8)</td>
</tr>
<tr>
<td>Neutral</td>
<td>1 (3.8)</td>
<td>1 (9.1)</td>
</tr>
<tr>
<td>Agree</td>
<td>3 (11.5)</td>
<td>1 (9.1)</td>
</tr>
<tr>
<td>Mean Perceived Barriers Score -20 - 20 (#, SD)</td>
<td>-7.93 (5.9)</td>
<td>-6.45 (6.6)</td>
</tr>
<tr>
<td>Mean number of barriers to care endorsed (#, SD)</td>
<td>1.69 (1.8)</td>
<td>2.27 (4.6)</td>
</tr>
</tbody>
</table>
Barrier Scores in Relation to ASD Diagnosis

The mean number of barriers to care endorsed by caregivers of ASD children was significantly higher than that for non-ASD caregivers ($t=3.84; df=76; p=0.00025$). The mean total perceived barrier score for the ASD children group was also significantly higher than that for the non-ASD group ($t=3.02; df=81; p=0.0034$). Though institutionalized ASD children, whose caregivers may perceive more barriers in obtaining dental care for their child, were not included in this study, the present sample is representative of the children seen in dental practices. The majority of the children were treated by pediatric dentists.

The number of barriers endorsed was also compared within the specific severity subsets. There was no significant difference in the number of barriers endorsed by level of severity of ASD ($F=2.7(2, 81); p=0.27$). The highest number of barriers to dental care was endorsed by the caretakers of children with severe ASD.

Finding Dentists that Can Accommodate ASD Child’s Behavior Needs as a Barrier

Multiple barriers were compared for caregivers of children with and without ASD. Though the majority of the caregivers in both the groups did not perceive the problems listed in Table 4 to be barriers to care, they did tend to agree that finding appropriate management of the child’s behavior could be a barrier. A significantly higher number of caregivers with ASD children agreed that their child was uncooperative, and that the problem with cooperation was a barrier ($\chi^2=15.22; p=0.0001$). Caregivers also reported that it was harder to control the behavior of an ASD child than a non-ASD child ($\chi^2=11.4; p=0.0007$).

The difficulty in finding a dentist comfortable with treating a child with ASD was a significantly higher barrier for the caregivers of the ASD group than the non-ASD group ($\chi^2=5.46; p=0.019$). This was also the most common barrier to care for children with mild ASD.
There was no significant increase in the endorsement rate for this particular barrier as the severity of ASD increased ($F_{(2, 81)}=0.79; p=.046$).

**2.3.6 Conclusions**

The majority of the caregivers perceived dental health to be important to very important in both the ASD and non-ASD caregivers. This study illustrates the many potential barriers faced by caregivers in getting dental treatment for their children with ASD. The number of barriers endorsed by caregivers of ASD children was greater than that reported by caretakers of non-ASD children. The most prevalent barriers reported by the caregivers of ASD children were the difficulty in finding a dentist who is comfortable in treating their child and the uncooperative behavior of their own child. There was no significant difference in the number of endorsed barriers by the level of severity of ASD. Interestingly, caregivers of severely affected ASD children did not report greater difficulty finding a dentist than did caregivers of less severely affected children.
CHAPTER III: DISCUSSION OF THE OVERALL RESULTS

This study is unique in many ways. First, it highlights the barriers from both the dentist’s and the caregiver’s perspective, both of which are important elements of a child’s dental care. This study also addresses a wide range of the spectrum of ASD seen by dentists in private practice and the results were interpreted while taking the severity of ASD in consideration. The study of the caregivers also included a group of caregivers of children with no ASD diagnosis for comparison. In this section, we will discuss some barriers from the perspectives of the dentist and the caregiver, and will also discuss how the special needs of an ASD children factor into their dental care.

3.1. Dental Provider Factors

General dentists see children in their practice (Barker, Mathu-Muju, Nash, Li, & Bush, 2012). The findings from previous studies indicate that most general dentists see more healthy children than children with special health care needs (Casamassimo et al., 2004; Newacheck, McManus, Fox, Hung, & Halfon, 2000). Studies also show that patients with ASD were the least preferred, amongst various other conditions, to be seen by general dentists in their practice (Adyanthaya et al., 2017; Dao, Zwetchkenbaum, & Inglehart, 2005). In the present study, 26% of the general dentists reported not treating any patients with ASD, while 74% reported treating some of these children. This is quite a high proportion of dentists who treat children with ASD, and much higher than the proportion reported by general dentists in the state of Michigan, where only 32% of the dentists reported treating patients with ASD (Weil & Inglehart, 2010).

The present study showed that general dentists perceive some barriers to providing care to children with ASD. The average number of barriers endorsed by dentists who reported treating
children with ASD was only marginally more than that reported by the group of dentists who do not see patients with ASD. Though this was not a statistically significant result, the study did identify some unique barriers, which were explored further. This minimal difference in the score of the two groups can be attributed to three factors. First, the dentists in the present study saw fewer than three (2.8) children with ASD per month. This number is relatively low in terms of dentist’s exposure to the ASD population. For example, the general dentists in the Michigan study reported seeing on average 4 patients with ASD per month (Weil & Inglehart, 2010). Second, in the present study almost 90% of the general dentists saw mild-moderate severity patients with ASD. Thus the general experience of treating ASD children for these dentists is that they are not particularly challenging, and thus the dentists may perceive few barriers to treating these children.

3.1.1 Insurance Reimbursements and Referrals

Children with special health care needs are at increased risk for unmet dental needs, especially those who are uninsured and those from poorer families (Lewis, 2009; Newacheck et al., 2000). Medicaid plays a critical role in the lives of children with special health care needs by ensuring access to affordable health care services that they need to stay healthy (Bachman et al., 2012). In this study more than three-quarters of the children with ASD (78.3%) were covered solely by a public/state insurance.

Low insurance reimbursement rates have been a factor for dental providers to decline participation in state insurance plans. The lack of specialists to whom Medicaid patients can be referred adds to the burden for the dentists who do participate in these plans (Logan et al., 2015). In the present study, 66.7% of the dentists seeing patients with ASD accepted public insurance.
More than half of the dentists who did not see patients with ASD accepted only private insurance in their practice. In the present study, lack of acceptable insurance was cited as a barrier to providing care by 43.5% dentists who did not see children with ASD and by 30% of those who did treat ASD patients.

One of the important findings of the present study was that more than half of the dentists, regardless of whether they treated children with ASD or not, felt that a lack of sufficient reimbursement for behavior management for ASD patients was a barrier to providing care to those patients. Children with ASD often require modifications in behavior management techniques and often require more time for their treatment. If insurance companies do not reimburse dentists sufficiently for their time and expertise, they will have little incentive to spend time in desensitizing these children or otherwise making provisions to accommodate their condition (e.g., seeing them over multiple appointments).

From a caregiver’s perspective insurance, and availability of dentists who can treat special needs patients, play important roles as well. In our study, 28.3% of the caregivers with ASD children agreed that it was hard for them to find a dentist who takes their dental insurance. This was a problem for only 5.4% of the caregivers of children without ASD. Though nearly three-quarters of the caregivers of both groups disagreed that it was difficult to get an appointment with a dentist, nearly 10% of the caregivers in both groups agreed that finding a dental specialist was a barrier. Finding a dentist who accepts their dental insurance was significantly more difficult for the caregivers of ASD children ($\chi^2=7.34$, df=1, p=0.0067). The lack of dentists treating this population results in longer wait times for those dentists who treat this population, which adds to the existing barriers for the caregivers (Liptak et al., 2008; Manning-Courtney, 2007).
3.1.2 Training and Experience of the Dentist and Staff

The difficulty in finding a practitioner with the appropriate skills to deal with children with special needs is a topic that emerges in both the medical and dental literature (Casamassimo et al., 2004; Krauss et al., 2003). One important barrier as perceived by the practitioners in previous studies was a perceived lack of training (Casamassimo et al., 2004; Krauss et al., 2003; Salama et al., 2011). In the present study, 36.4% of the dentists who reported not seeing patients with ASD agreed that insufficient training in this field was a barrier for them in providing care to this population. Only 16% of those dentists seeing patients with ASD reported that lack of training was a barrier. The main source of training for the dentists who treats patients with ASD in our study was from the experience in treating these patients in their practice (72.5%).

A significant association was found in a study between the experience of the dentist and the frequency with which they reported seeing children with special needs (Adyanthaya et al., 2017). The only study reporting barriers to providing care specifically for children with ASD was done by Weil et al. Survey data from 162 general dentists in Michigan and 212 pediatric dentists across the United States showed that 89% of pediatric dentists and 32% of general dentists treat patients with ASD. The dentists disagreed that their pre-doctoral dental education had prepared them well to treat patients with ASD (Weil & Inglehart, 2010). Although 28.4% of the dentists in our study reported getting some training in dental school, the majority of the dentists did not consider that insufficient training was a barrier for treating ASD children.

Pediatric dentists in the United States receive two extra years of advanced training in the treatment of children and those with special needs after their four years of dental school. The principal barrier faced by most pediatric dentists while transitioning the special needs children to
an adult dentist is the availability of general dentists and the willingness of other specialists to accept these patients (Nowak, 2002). The frequency with which dentists use appropriate behavior management strategies when treating patients with ASD is correlated with the quality of their educational experiences (Weil & Inglehart, 2010).

Certainly, the delivery of care to developmentally disabled youth is perceived as difficult, particularly to those with relatively little experience in treating these children. A study of 534 dentists in Greece, the majority of whom were general dentists, reported that the provision of oral health care to persons with physical and intellectual impairment demands a lot more time and is hard to accomplish (Gizani, Kandilorou, Kavvadia, & Tzoutzas, 2014).

### 3.1.3 Guidelines for Treating Children with ASD in a Dental Setting

To our knowledge, no studies have been conducted to evaluate the effectiveness of standardized guidelines for the treatment of patients with ASD. Evidence of strategies that work well in the dental setting is limited. The use of picture books to help prepare ASD children for a visit to the dentist has resulted in improvements in cooperation during dental treatment (Backman & Pilebro, 1999). Similarly, other behavior management strategies like tell-show-do and desensitization have been used for the behavior management of children with ASD with some effectiveness (Fakhruddin & El Batawi, 2017).

The D-Terminated Program of Familiarization and Sequential Tasking has been shown to help dentists accommodate patients with autism in their practice (AlHumaid, Tesini, Finkelman, & Loo, 2016). Though the effectiveness of techniques like the D-Terminated Program and visual demonstrations have been discussed in the literature, large-scale studies have not been conducted. At present, resources for dentists are limited. A review article by Gandhi and Klein
discusses various ways to manage children with ASD in a dental setting (Gandhi & Klein, 2014), but there are no published guidelines from the American Academy of Pediatric Dentistry (AAPD) or the American Dental Association (ADA) establishing gold standard techniques for managing these patients. Health care providers' knowledge of evidence-based recommendations for providing care increases the likelihood of better outcomes for children with autism spectrum disorder (Bultas, Johnson, Burkett, & Reinhold, 2016). Thus, efforts to establish standard guidelines and research in the area of testing various behavioral strategies for ASD patients in the dental setting would be an important step towards improving care for this population.

3.2 Caregiver Factors

Caregivers play an important role in providing oral care at home, and they must be included in the efforts to improve oral health outcomes for children, especially those with ASD. The mean number of barriers to care endorsed by caregivers of ASD children was significantly higher than that for non-ASD caregivers. Difficulty in accessing dental care for children with ASD was reported by 25% of the parents in a study by Marshall et al. (Marshall et al., 2010). A study by Lewis et al. conducted for four focus groups of parents with children with ASD showed how caregivers and parents are valuable partners in determining the unique oral care needs of their child with ASD (Lewis et al., 2015). It is thus important to take into consideration the caregivers’ perspective in managing the care for children with ASD.

3.2.1 Parental Fear/Motivation

Parental fear may subconsciously be transferred to the child. Maternal anxiety before the child's dental treatment is significantly associated with their child's dental fear (Karibe et al., 2014). Dental fear in young children is prevalent (Klingberg, 1995) and can lead to behavior
management problems. This can further negatively affect the dental health of the child and is associated with missing dental appointments (Klingberg, 1995).

Interestingly, the majority of the caregivers (79.5%) in the present study did not report that dental fear was a barrier for their child receiving dental care. In fact, a large majority of the caregivers here reported seeing the dentist every 6-12 months. Nor were the children studied here particularly frightened by the toothbrush or oral hygiene practices. The majority of children in both groups were reported to be brushing their teeth at least once a day. More than 90% of the caregivers in both groups in this study reported oral health to be “important.” Along similar lines, the perceived status of their child’s dental health was good to excellent for 72% of the ASD caregivers and 86% of the non-ASD caregivers. The relatively low number of barriers to care reported in this study may be because the sample that was surveyed had good access to resources and considered oral health to be important.

The lack of motivation of caretakers was reported as one of the important barriers by the practitioners in a previous study (Adyanthaya et al., 2017). In the present study, 27% of the dentists who treat children with ASD reported that caregivers do not reliably show up for appointments. If a child with ASD has a supportive family, who is proactive and takes part in the management of common concerns, the health outcome for the child tends to be better (Bultas, Johnson, et al., 2016). It is likely that outcomes in dentistry will likewise be better when the child with ASD has strong family support.

3.2.2 Time constraints/Job commitment/Transportation

Nelson (2011) reported that 9% of the parents/caregivers of patients with ASD they studied faced difficulty in traveling to the dentist’s office, and 15% experienced difficulties in
accessing dental care close to their homes (Nelson et al., 2011). Wiener et al. (2016) used the data from the National Survey of Children with Special Health Care Needs, 2009-2010, to evaluate the caregiver’s burden in accessing preventive dental care for children with ASD, developmental disability and other mental health conditions. In their study 40% of the caregivers reported financial burden, 20.3% reported employment burden, and 10.8% reported time burden. A higher percentage of the caregivers who reported financial, employment, and time-related burdens also reported that their special needs children did not receive needed preventive dental care (Wiener et al., 2016). In the present study, 28% of the caregivers with an ASD child reported that they had employment-related time constraints that constituted a barrier to dental care for their child. Less than 5% of the caregivers in both the groups reported transportation-related barriers.

3.3 Patient Factors

Autism varies widely in symptoms and severity, and some people have coexisting conditions such as intellectual disability or epilepsy. They can be among the most challenging of patients in a dental office. The severity of ASD is based on two important characteristics: social communication impairments, and restricted, repetitive patterns of behavior. It is important for the dental practitioner to be aware of the symptoms that could interfere with the care and treatment of children with ASD in a dental clinic.

3.3.1 Cooperation/Behavior of the Child

A frequent finding is that medical procedures performed on patients with intellectual disabilities are more time-consuming, and require more physical and emotional involvement, both from parents and medical staff, due to poor cooperation (Burtner et al., 1990). Studies
suggest that most general dentists see a limited number of special needs patients from all age
groups. Patient behavior is a common reason for not seeing more special needs patients (Salama
et al., 2011). Negative behavior was the most common barrier to dental care in the ASD group in
multiple studies (Barry et al., 2014; Brickhouse et al., 2009; Lai et al., 2012).

In our study, 25% of the general dentists perceived that ASD children are uncooperative
and 45% agreed that their treatment takes longer and/or they require extensive behavior
management as compared to the healthy children. Negative behaviors may include uncooperative
behaviors in the dental clinic such as like kicking, screaming, and unwillingness to enter the
dental clinic, or resistance to toothbrushing at home. Children with uncooperative behavior are
less likely to have a regular dentist according to one study (Brickhouse et al., 2009).

In the present study the level of cooperation at the dentist was perceived as fair to poor by
26% of the caregivers with a child with ASD. Non-ASD children (11%) were less likely to be
perceived as uncooperative at the dentist. The caregiver’s perception of the behavior of their
child at the dentist was the poorest for a severely autistic child (55.6%). Only 15.4% of those
with mild autism and 27.3% of those with moderate autism, were reported by their caregiver of
showing fair to poor cooperation at the dentist.

One of the most important factors in good dental health is rigorous and regular home
care, in addition to timely dental visits. A child with ASD may have oral aversions due to
sensory disturbances. These aversions may interfere with proper home care and with the ability
to cooperate with a dentist doing an oral examination. Stein et al. reported that children with
ASD were more likely to object to a toothbrush in the mouth compared to children with other
disabilities. In their survey, 50% of the parents of children with ASD reported sensory processing
problems, which impacted negatively on the child’s dental care provision. They also concluded that children with autism spectrum disorders experience greater difficulties and barriers to care in both the home and the dental office than their typically developing peers (Stein et al., 2011; Stein et al., 2012).

In the present study, 34.8% of the ASD children and 54% of the non-ASD children were reported to be cooperative at home for toothbrushing (see Table 3). Surprisingly, only 13% of the ASD children and 19% of the non-ASD children were reported by their caregivers to be uncooperative with toothbrushing at home. This level of cooperativeness with home oral hygiene in ASD children may not be typical, and is often dependent on the severity of the syndrome.

One study found that 75% of the special needs children were cooperative in a traditional dental setting, yet 40% of their caretakers experienced difficulty in locating a dentist willing to treat them (Hagglund, Clark, Conforti, & Shigaki, 1999). In the present study, the uncooperative/unpredictable behavior of their child was the most prevalent barrier perceived by caregivers with a child with ASD. While 39% of the caregivers with ASD agreed to this, only 2.7% from the non-ASD group agreed that uncooperative behavior was a barrier to care for their children. 37% of the caregivers with ASD children felt that it was hard to control their child’s behavior and only 5% of the typically developing children’s caregivers agreed that his was a barrier to dental treatment. Negative behavior was a more potent barrier to dental care for the severely autistic child (56%) than that for the mildly autistic children (31%).

3.3.2 Medical Condition of the Child and Interventions

There is no cure for ASD (Jones, Cork, & Chowdhury, 2006), but early interventions, such as ABA (Applied Behavioral Analysis) treatment programs for individuals with autism are
supported by a significant amount of scientific evidence and are therefore recommended for use to improve their social and communication skills (Granpeesheh, Tarbox, & Dixon, 2009). 87% of the children with ASD in this study had Individualized Education Programs (IEP) in school, in which ABA is used to teach adaptive behaviors. This rate of individualized programming in school is similar to that seen in another study of ASD children (Becerra et al., 2017).

Childhood IQ and early language ability appeared to be the strongest predictors of later outcomes (Magiati, Tay, & Howlin, 2014). Several prospective studies confirm that delays in communication and language development are apparent in early life in children with ASD (Mitchell et al., 2006). The development of linguistic ability, or lack of it, shows broad variability within the ASD spectrum. Young children with ASD have been shown to exhibit more profound delays in receptive language than in expressive language (Weismer et al., 2010).

In this study, amongst the ASD children 76% were verbal and 24% were non-verbal children.

The mean number of endorsed barriers for the verbal children was 1.9 ($SD=1.8$) and 2.6 ($SD=2.3$) for the non-verbal children ($t=-1.05; df=44; p =0.29$).

Pharmacological therapy is also used to target symptoms such as anxiety or aggression in individuals with autism, but at present there are no medications to improve the core symptoms of this condition (Nicopoulos et al., 2007). In the present study 52% of the children with ASD had some other associated medical problems, while only 19% of those without ASD had medical problems. In both groups, 8% of the caregivers felt that impairment due to other medical problems in the child was a barrier to their dental care. From a dentist’s perspective, a complex medical history in an ASD child was perceived to be a barrier for 27% of the dentists who treat children with ASD and 35% of those who do not treat children with ASD.
Many children with ASD are high functioning and milder on the spectrum, requiring no difference in their management from typically developing children in a general dental practice. Educating the dentists about ASD and training them to manage these children in the practice will be an important step in bridging the gap and expectations of caregivers and dentists, thus improving barriers to dental care for this cohort.
CHAPTER IV: FURTHER WORK AND RECOMMENDATIONS

4.1 Limitations of the Current Study

We recognize certain limitations of our study, which are as follows:

1. This research may have been limited by the nature of the identification of potential barriers to dental care for children with ASD. We cannot be sure that all potential barriers to care were tapped by this survey.

2. We could not re-administer the surveys to the caregivers who participated and therefore could not evaluate the test-retest reliability for the responses that were provided.

3. This study did not record the barriers specific to various procedures in dentistry depending on their difficulty level or specific to the age of the child treated by the general dentists.

4. Caregivers who didn’t speak English were excluded from this study. This may have limited the generalizability of the results by excluding some potential participants. However, a lack of spoken English may, in itself represent a barrier to dental care. Therefore, the inclusion of this group may have potentially introduced confounders into the study. The overall prevalence of barriers to dental needs in children with ASD may be underestimated.

5. The study and control group children were not age- and gender-matched. Nor were data on the sex of the child collected. Though this does not directly affect the study goals, an analysis by gender would have been helpful to determine if the number of type of barriers to care endorsed barriers were related to the gender of the child.
6. Selection bias could be a limitation in this study, since the families who had their children treated in the Autism Center may have had better access to healthcare than the average ASD child. In particular, institutionalized children and those not treated at the center may have many more barriers to care, but were not included in this study.

4.2 Recommendations to Improve Barriers to Dental Care for Children with ASD

This research was affected by a number of limitations as previously outlined. Further investigation involving the recruitment of larger number of participants would allow a subgroup analysis according to the age and ASD severity of the children. This would determine whether barriers to dental care are age and/or severity-related. It would also be desirable to include a more diverse group of dentists, especially those from specialty areas, given the difficulty in finding dental specialists who treat children with ASD. Based on our findings, some specific recommendations for the caregivers of ASD children and the dental care providers are offered.

4.3 Recommendations for the Dental Care Providers

It is important for dental health care providers to be familiar with ASD and its associated clinical manifestations, so that they can tailor to their patients’ individual needs and use the appropriate behavior management strategies to gain maximum cooperation.

Training in caring for special needs patients seems to be inadequate for dental students (Ahmad, Razak, & Borromeo, 2015; Vainio, Krause, & Inglehart, 2011). Though many patients are referred to a hospital setting for their behavior and/or medical management, there are many patients on the spectrum who are cooperative, and can be seen in dental offices regularly for preventative care. As these families already face enormous emotional and financial challenges,
allowing for early intervention and preventive care for these more cooperative patients can have a significant impact on their overall health and well-being.

As noted from this study, one of the most important barriers for dentists is their experience and training, thus pilot training programs in caring for patients with ASD should be incorporated into the dental school curriculum. Connections may be established for dental students to go on rotations at off-site institutions or hospitals to enhance their clinical experience in caring for patients with special needs. General and pediatric dentists should be encouraged to attend continual education courses for the updates on current evidence and behavior management of children with special needs in dental settings. Another way to improve the training of dentists in the care of children and adults with disabilities is through the creation of a postdoctoral residency program in Special Care Dentistry (Hicks, Vishwanat, Perry, Messura, & Dee, 2016).

4.4 Recommendations for the Caregivers

Children with ASD prefer routines and schedules. Going to a dentist involves new experiences, involving meeting new people, and exposure to a new environment. Such social situations could be especially challenging for an autistic child. Visiting a dental office in advance, and letting the dentist know some of the likes/dislikes/triggers for the patient can be helpful. Daily brushing at home and desensitizing the child to the sensations of a toothbrush in his/her mouth, can both help with sensory behavior adaptation as well as maintaining good oral hygiene. A few days before the dentist’s appointment, parents can also prepare the child for the visit to the dentist by showing them pictures of the dental office and the dentist. As discussed earlier, preparation through the use of pictures has shown to be effective in increasing the cooperation of autistic children during dental treatment (Backman & Pilebro, 1999).
Recommendations for the other Health Care Providers

A pediatrician sees a child for 11 well-child visits by their third birthday. The provision of continuous primary care, supports the development of trust with parents, provides an opportunity for screening, and early intervention for children with ASD. Early referrals and follow-ups on establishing a dental home by age one, can be an important step towards preventing dental disease to happen by counseling and successive acclimatization.

A study by Lai et al. found that the majority of the children with ASD (95%) received regular medical care from their family physicians, while 75% had a regular dental visit at least every six months (Lai et al., 2012). An interdisciplinary team approach with the child’s physician may help to manage the behavior of the child with ASD, which was reported to be a major barrier to dental care. An oral health assessment may be incorporated into a physician’s visit and an appropriate referral base or connection may be established early on.

Collaboration among other health care professionals (developmental pediatricians, psychologists, speech and language pathologists, etc.), autism organizations, and dental care professionals is needed to improve the oral health outcomes for children with ASD. For example, physical therapy sessions for ASD children might include toothbrushing plans designed in consultation with a dental professional. Home based services for early interventions like Birth23 in the state of Connecticut should look into including oral health care delivery at home. This would help in establishing a dental home for these children early on by age one as recommended by the AAPD.
CHAPTER V: OVERALL CONCLUSION

The present study gives an insight into the barriers to dental care experienced by children with ASD. From the results of this research, it can be concluded that there are barriers that exist for both the general dentists and the caregivers of children with ASD in providing dental care.

1. General dentists face many barriers in treating children with Autism Spectrum Disorders. The most commonly endorsed barriers were the lack of available guidelines, the lack of sufficient reimbursement for behavior management of the ASD children, and difficulty in managing the behavior of a child with ASD.

2. The mean of the total perceived barriers score for the two groups of dentists was significantly higher for those who did not see these children in practice.

3. The majority of the caregivers perceived dental health to be important to very important in both ASD and non-ASD group children.

4. The mean number of barriers to care endorsed by caregivers of ASD children and the mean total perceived barrier score was significantly higher than that for non-ASD caregivers. The most prevalent barriers endorsed by the caregivers of ASD children were the difficulty in finding a dentist who is comfortable in treating their child (37%) and the uncooperative behavior of their child (39%). The behavior of the child in the non-ASD group was only noted by 5% of the caregivers.

5. The caregivers of the children with severe ASD perceived having the most barriers to care. Negative behavior of the child was a barrier to care for more severe ASD children than those
who were less severe on the spectrum. A significantly higher number of caregivers with ASD children agreed that their child was uncooperative and that such behavior was a barrier.

6. The difficulty in finding a dentist comfortable with treating a child with ASD was the most common barrier to care for children with mild ASD, but not significantly different from the severe ASD children. This was a significantly higher barrier for the caregivers of the ASD group than the non-ASD group.

7. Significantly more ASD children were in a special education program at school than non-ASD children.

8. Significantly more children with ASD had co-morbidities than non ASD children.

It is hoped that the results of these studies will help in developing interventions that will help alleviate the gap between the understanding of barriers from the two sides and improve the dental experience for this vulnerable group. Autism Spectrum Disorder as a diagnosis in itself is not a definite indication of difficulty in the dental environment. Every child is unique, and differs in terms of severity, co-morbidities, behavior, past experiences, interventions, home care, and many other factors. It is thus important for the dentists to identify the individual as a combination of unique strengths and differences. Both dentists and caregivers can help work together to manage the barriers to meeting the dental needs of a child with autism, and play a key role in helping these children achieve oral health.
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Appendix 1 – Consent Form for the Dentists’ Study

To: General and Specialist Dentists of New England
From: Mark Litt, Ph.D., Dept. of Oral Health & Diagnostic Sciences, UConn SDM
Re: “Barriers to Dental Care for Children with Autism Spectrum Disorder: Dentist Perspective”

Thank you for considering participating in this study of dentists’ barriers to providing dental care for children with ASD.

Purpose

The purpose of this study is to evaluate the barriers faced by dentists in providing dental care to children with ASD.

The increasing prevalence of autism spectrum disorder (ASD) suggests that dental practices will be seeing patients with this diagnosis more frequently. Although patients with ASD have dental needs similar to those of other patients, the symptoms of the disorder may influence the ability of dental practitioners to provide necessary care. Dental professionals may find it difficult to treat children with ASD in the office due to lack of experience/education or skills in managing behavior of patients with ASD. The proposed study is intended to assess what barriers exist for dentists in providing care to these patients, using a self-report questionnaire. Results of this study may help to develop guidelines for management, educational changes and modification in reimbursement schedules for practicing dentists in order to provide better care to these patients.

Participation

Any participation is voluntary. Completion and return of the survey implies consent on your part. You may elect not to participate at all. If you do wish to participate, you may skip any question for any reason. It will take approximately 3-5 minutes of your time. No identifying information will be collected about you.

Questions or Concerns

Any questions or concerns may be addressed to me, by phone, mail or e-mail. Thank you again for your time and consideration.

Please put no identifying information on the survey. When finished, place it in the box at the UConn School of Dental Medicine table.

Mark D. Litt, Ph.D.
Professor
(860) 679-4680
Litt@nso.uche.edu
### Dentists’ Questionnaire

**Issues in treatment of children with ASD**

#### 1. Are you a
- ☐ Male
- ☐ Female

#### 2. Dental Practice:
- ☐ 1. General Dentist
- ☐ 2. Pediatric Dentist
- ☐ 3. GPR
- ☐ 4. Endodontist
- ☐ 4. Oral surgery
- ☐ 5. Orthodontist
- ☐ 6. Periodontist
- ☐ 7. Other (Please specify) _________

#### 3. For how many years have you practiced clinical dentistry? __________

#### 4. Do you treat children with Autism Spectrum Disorder?
- ☐ Yes
- ☐ No

**If yes:**

#### 4a. Approximately how many patients with ASD do you see per month? __________

#### 4b. What type of children with ASD do you treat?
- ☐ Mild
- ☐ Moderate
- ☐ Severe

#### 5. What type of dental insurance do you take (check all that apply)?
- ☐ Private insurance
- ☐ Public insurance (Medicaid/Health Choice)
- ☐ Private insurance

#### 6. Your training in ASD behavior management mainly comes from (choose the most significant for you):
- ☐ Experience in practice
- ☐ Dental School
- ☐ Residency/Fellowship
- ☐ CME Courses
- ☐ Other

#### 7. The following statements describe possible barriers to providing care to children with Autism Spectrum Disorder. For each item indicate whether that statement applies to you.

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I usually do not get patients who have ASD in my practice.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Child’s behavior is unpredictable/uncooperative/aggressive.</td>
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<tr>
<td>3. Do not feel comfortable in treating children with ASD due to less experience during training.</td>
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<tr>
<td>4. Lack of practice guidelines to treat children with ASD</td>
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<tr>
<td>5. Lack of proper reimbursement from insurance for behavior management/desensitization of children with ASD</td>
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<tr>
<td>6. It usually takes too long to get small work done, office flow does not allow time to spend time demanded for desensitization.</td>
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<tr>
<td>7. Complex medical problems for children with ASD</td>
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<tr>
<td>8. Our office does not take state insurance patients</td>
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<tr>
<td>9. Caregivers are unable to come for regular appointments</td>
<td></td>
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<tr>
<td>10. Office staff not trained to manage children with ASD</td>
<td></td>
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</tr>
<tr>
<td>11. Others (Please specify): __________________________________________</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Appendix 3: Consent Form for the Caregivers’ Study

THE UNIVERSITY OF CONNECTICUT SCHOOL OF DENTAL MEDICINE
DIVISION OF BEHAVIORAL SCIENCES & COMMUNITY HEALTH - MC3910
FARMINGTON, CT 06030

To: Parents or Caregivers of Children Diagnosed with an Autism Spectrum Disorder
From: Mark Litt, Ph.D., Dept. of Oral Health & Diagnostic Sciences
Re: “Barriers to Dental Care for Children with Autism Spectrum Disorder: Caregiver’s Perspective”

Thank you for considering participating in this study of caregiver’s barriers to providing dental care for children with Autism Spectrum Disorder (ASD).

Purpose

The purpose of this study is to evaluate the barriers faced by caregivers to providing dental care to children with ASD.

Children with ASD often have difficulty with communication or sensory stimuli, and may act out or tantrum when confronted with unexpected situations. These symptoms of ASD can significantly interfere with the delivery of dental care, and may therefore affect their dental health. These symptoms, when they appear in the dental environment, have an impact on the caregivers as well. Caregivers may be concerned about both the child having an unpleasant experience and about their own embarrassment in the event the child is non-compliant or has a behavioral outburst. The proposed study is intended to assess the barriers that exist for caregivers in providing care to children with ASD, using a self-report questionnaire. Results of this study will tell us what, if any, additional support may need to be provided to caregivers of children with ASD to assure optimal dental care for these children.

Participation

Any participation is voluntary. Completion and return of the survey implies consent on your part. You may elect not to participate at all. If you do wish to participate, you may skip any question for any reason. It will take approximately 7-10 minutes of your time. No identifying information will be collected about you or your child.

Questions or Concerns

Any questions or concerns may be addressed to me, by phone, mail or e-mail. Thank you again for your time and consideration.

Please put no identifying information on the survey. When finished, place it in the box at the Clinic desk.

Thank you.

Mark D. Litt, Ph.D.
Professor
(860) 679-4680
Litt@nso.uche.edu
Appendix 4: Caregivers’ Study Questionnaire

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  Has your child been diagnosed with Autism Spectrum Disorder (ASD)?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>If yes</td>
<td></td>
</tr>
<tr>
<td>1a Is your child mostly</td>
<td>Verbal, Non verbal, Do not know</td>
</tr>
<tr>
<td>1b Does your child physically harm himself or anyone around him?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>2  What is the age of your child?</td>
<td>Years</td>
</tr>
<tr>
<td>3  Does your child have any other medical conditions?</td>
<td>No, Yes (specify)</td>
</tr>
<tr>
<td>4  If school age, what educational services does your child receive in school? (Please check ALL that apply)</td>
<td>Do not know, Individualized Educational Program (IEP), 504 Plan, Community Alternate Program (CAP), Other (Please specify)</td>
</tr>
<tr>
<td>5  What type of dental insurance does your child have?</td>
<td>Private insurance, Public insurance (Medicaid/Health Choice), No dental insurance</td>
</tr>
<tr>
<td>6  What is your educational level?</td>
<td>Didn’t complete High School, High School Graduate or GED, 2 year degree or some college (Community College, Technical School), Completed College, Other (Please specify)</td>
</tr>
<tr>
<td>7  What best describes your child’s teeth brushing routine?</td>
<td>Does not brush/let anyone brush his/her teeth, Sometimes brushes himself and lets others brush after if needed, Brushes/lets brush easily and regularly</td>
</tr>
<tr>
<td>8  How often does he brush his teeth?</td>
<td>Once or more a day, Once every two-three days, Less than once a week, Not sure</td>
</tr>
<tr>
<td>9  How cooperative do you think your child is with dental exams and teeth cleaning?</td>
<td>follows dentist’s instructions and let them clean most of the time, follows some instructions, gets cleaning done with some resistance, follows instruction to some extent, opens mouth but does not let anything in his/her mouth easily, does not sit in the chair, resists everything and fights, unable to get anything done unless restrained</td>
</tr>
<tr>
<td>10 On a scale from 1 to 5, how important do you think is your child’s dental health?</td>
<td>Not important, 1, 2, 3, 4, 5 (Very important)</td>
</tr>
</tbody>
</table>
11. In your opinion, what is the status of your child’s dental health?
- □ Excellent
- □ Very good
- □ Good
- □ Fair
- □ Poor
- □ Has no natural teeth

12. How often does your child visit a dentist?
- □ He/she has never seen a dentist
- □ Only during pain/emergency
- □ Every 6-12 months

13. What type of dental office does your child go to for dental care?
- □ General Dentist Practice
- □ Pediatric Dentist
- □ Hospital Dental Clinic (CCMC/Yale, etc)
- □ Community Health Center
- □ Other (Please specify)

14. There are many reasons caregivers find it hard to take their child to the dentist. For each of the following please indicate whether you agree that that reason applies to you.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Your own fear of going to the dentist</td>
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<tr>
<td>2. Hard to find dentist who takes my insurance nearby/ no insurance</td>
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<td>3. Lack of transportation</td>
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<td>4. Child’s behavior is unpredictable/uncooperative</td>
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<td>5. Time constraints due to other family/job commitments</td>
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<td>6. There is no urgent need for my child to see a dentist</td>
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<td>7. Difficulty in getting an appointment in reasonable time</td>
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<tr>
<td>8. Not able to find a dentist who is comfortable in treating children with ASD</td>
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<td>9. Child is very sick due to other medical problems</td>
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<td>10. It’s hard to control my child’s behavior</td>
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<tr>
<td>11. Difficulty finding care for specialized problems (e.g., root canal, gum problems, oral surgery)</td>
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</tbody>
</table>