Predicting Successful Dental Examination for Children with Autism Spectrum Disorder

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Abstract

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Purpose: To evaluate characteristics of children with Autism Spectrum Disorder (ASD) that were associated with the ability to tolerate a dental examination following desensitization therapy.

Methods: Caregivers of 168 children with ASD who attended a university-based pediatric dental clinic completed pre-visit questionnaires. Questions included demographic information, medical and dental history, behavioral characteristics, communication and self-care abilities. Children visited the clinic for an initial consultation followed by subsequent desensitization visits. The end goal was receiving an oral examination while seated in a dental chair. Bivariate associations with ability to receive a quality dental exam were tested using modified poisson regression. The statistical significance level was set to $p<0.05$.

Results: Participants were 83% male, 4-18 years old. Eighty-eight percent allowed an oral exam when seated in a dental chair; 77.4% within 1-2 visits and 87.5% within 5 or less visits. Multiple factors predicted successful dental examination: (1) ability to be involved in group activities (RR 1.18, *P*=.02); (2) verbal communication (RR 1.17, *P* =.002); (3) understanding of most language (RR 1.14, *P*=.02); (4) moderate caregiver-rated ASD severity (RR 1.24, *P*=.04); (5) ability to dress self (RR 1.27; *P*=.04).

Conclusion: Of those who were able to learn to accept dental care, most received dental examination within 1-2 desensitization visits and the majority did it by the 5th visit. Social, communication, and self-care abilities were strongly and positively associated with ability to receive dental examination after desensitization.

Keywords: Autism, Autism Spectrum Disorder, successful dental examination, behavior management

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LIST OF ABBREVIATIONS

ABA = Applied Behavior Analysis.

ASD = Autism Spectrum Disorder.

BGT = Behavior Guidance Techniques.

CDC = The Centers for Disease Control and Prevention.

DIR = Developmental, Individual Differences.

DSM = The American Physiciatric Association's Diagnostic and Statistical Manual of mental Disorders.

RR = Relative Risks.

SADE = Sensory Adapted Dental Environments.

TEACCH = Treatment and Education of Autistic and Related Communication-handicapped Children.

TSD = Tell-Show-Do.

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DEDICATION

To my mother, Tina for always remembering to keep me fed and mentally healthy.

To my husband Houth and children, Vanessa, Zander, Avelin, and Azalea. This would not have been possible without the sacrifice and support of my family.

Chapter 1: INTRODUCTION

Prevalence of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is one of the most common developmental disorders diagnosed in children worldwide. According to The Centers for Disease Control and Prevention (CDC), ASD occurs in one out of 68 children, but is not related to ethnicity, nationality, or socio-economic status. It is approximately five times more common in boys than girls.[1]

Diagnosis of ASD

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5) provides the most recent diagnostic criteria for ASD. Diagnosis includes deficits in social communication and interaction and restricted, repetitive patterns of behavior, interests, or activities that cause significant impairment in function.[2] This often results in abnormalities of cognitive function, learning ability, and sensory processing.[1, 3] ASD is diagnosed primarily by observation and by psychological testing of a child's social and physical behavior, as well as language skills during infancy and childhood. To date, there are no medical tests (e.g. blood tests) that can be performed to diagnose ASD.[3] The revised DSM-5 criteria are geared toward early diagnosis, recognizing that although most children are currently diagnosed after age four, a reliable diagnosis is possible around age two.[1] Early diagnosis is critical, as early therapeutic intervention is associated with the best long-term neurocognitive and behavioral outcomes.[1]

Barriers to Dental Care

The prevalence of ASD has increased, and more dental practitioners now encounter patients with ASD in their practices. Although a high percentage of children with ASD have

visited a dentist (97%), many do not receive dental care necessary to maintain good oral health.[4] The prevalence of unmet dental need in children with ASD is currently 12% to 15%, compared with approximately five percent of typically developing peers.[4-7] Child cooperation, cost of dental care, lack of insurance, not having a medical home, and difficulty finding a dental provider are commonly reported treatment barriers.[4, 7]

By definition, children with ASD have impairment in communication and sensory modulation, which may make interacting with the dental team challenging. Basic behavior guidance techniques (BGTs) such as tell-show-do (TSD), positive reinforcement, distraction, and voice control that are effective with typically developing children may not be as effective with this population.[8-10] Circumstances that overwhelm the child's senses can also lead to avoidance reactions which may escalate to physical aggressiveness.[2, 4, 11] Consequently, parents may be reluctant to seek care and dental providers may avoid providing necessary treatment.

Behavior Guidance for Children with ASD

A wide variety of BGTs have been employed to facilitate dental care for children with ASD, however the literature on this topic is far from conclusive. Most publications are expert opinion or small studies.[9, 10, 12-17] As a result of the difficulties experienced in caring for these children, advanced behavior guidance techniques such as protective stabilization, procedural sedation, and general anesthesia have commonly been used.[9, 10, 13] Though these techniques are generally quite effective, they can place the patient at risk for physical and psychological complications. It is also important to remember that while these BGTs may solve immediate needs, they do not promote long-term acceptance of dental care.

Educational and Behavioral Approaches to Care

To help address these concerns, contemporary dental behavior management strategies have begun employing approaches that are used in educational settings.[8, 13, 18] Such strategies typically focus on promoting compliance and pro-social behaviors in the dental office, recognizing that the ability to receive dental care is a life skill which may be learned over time. Treatment protocols have included standard techniques such as positive reinforcement and tell-show-do,[17] visual preparation aids,[14-16, 19] applied behavior analysis (ABA),[8] developmental, individual differences (DIR), relationship based approach,[20] treatment and education of autistic and related communication-handicapped children (TEACCH),[21] individualized reinforcement,[14, 22] and sensory adapted dental environments (SADE).[23]

Other approaches for providing dental care for intellectually disabled children and adults have included combining progressive desensitization and individualized reinforcement.[14, 24-26] Many of these programs were not focused exclusively on children with ASD, yet their principles may prove beneficial in this population.[27] In such programs, the patient is gradually exposed to aspects of the dental visit that produce anxiety and provided with positive reinforcement through individualized rewards.[28] This reduces the patient's stress response and improves compliance in dental settings. Treatment programs that employ desensitization and exposure approaches have shown promise, however research investigating these approaches has varied widely in design.[21, 27, 29]

Predictors of successful examination

Previous studies have explored patient characteristics that predict cooperation during dental procedures. Variables such as increased communication skills (verbal ability, reading

skills),[9, 30] higher cognitive functioning,[9, 21, 30] greater ability to perform self-care,[9] and increased age[9, 30-32] are associated with improved compliance with dental care. In contrast, a high level of challenging behaviors,[30] sensory over-responsivity,[33] comorbid medical conditions,[9, 31] and residence in a group home[34] are associated with poorer acceptance of dental procedures[9, 10, 13, 15-17, 19, 21, 33, 35, 36]. (Appendix A) To date, however, there is little research that describes characteristics that predict cooperation during dental procedures in detail and evaluates these characteristics under a controlled treatment condition. Additionally, there is a lack of knowledge regarding which children are most capable of learning to accept dental examination through educational and behavioral approaches such as progressive desensitization. Such an approach could enable clinicians to successfully implement programs that teach children to receive dental care.

Study Purpose

The primary purpose of this study was to determine characteristics of children with ASD that are associated with the ability to receive a quality dental examination. This controlled treatment condition was defined as the child's ability to sit in a dental chair and open his/her mouth long enough for a complete clinical examination with a dental mirror. This study also aimed to evaluate the effectiveness of a dental desensitization program for children with ASD.

Chapter 2: METHODS

Design

In this prospective cohort study, we collected data using a comprehensive pre-visit information intake form completed by the caregiver. A detailed chart abstraction of each clinical visit was conducted to quantify: (1) the child's ability to tolerate a quality dental examination. (2) The number of desensitization visits required before a child was able to tolerate a dental examination as defined above.

This study was approved for human subjects by the University of Washington Institutional Review Board (HSD #49134).

Subjects

A total of 168 children with ASD were determined to be eligible for inclusion during the 36 month study period (1/1/12 - 1/1/15). Inclusion criteria were: (a) ASD diagnosis by a physician; (b) children aged 4-21 years old; (c) complete pre-visit questionnaire (d) participation in a dental treatment program for children with ASD at the University of Washington Center for Pediatric Dentistry (UW CPD).

Participants in the pre-cooperative age group (0-3 years old), those with incomplete chart entries or pre-visit intake forms, and patients with non-English speaking caregivers who were unable to complete the intake form were excluded from the study. We excluded a total of 51 participants.

Procedure

Caregiver Questionnaire

Prior to each child's initial clinical visit, a questionnaire was mailed to the family and returned to the clinic once complete. A total of 34 questions provided detailed information regarding child's demographic characteristics, language spoken, living situation, caregiver-rated ASD severity, medical diagnosis and history, history of therapies (e.g. behavioral, physical, speech, or occupational therapy), behavioral characteristics, communication skills, self-care abilities, mood, and previous dental experiences. (Appendix B)

A five-point Likert scale was used to assess the child's behavioral characteristics, self-care abilities, and communication skills. Caregivers were asked to rate their child's behavioral characteristics as *not able* (1), *infrequently able* (2), *sometimes able* (3), *frequently able* (4) or *able all the time* (5) for each of six social skills. To assess the child's self-care abilities, caregivers were asked to rate their child as *totally independent* (1), *needs verbal coaching/prompting* (2), *needs occasional help* (3), *totally dependent* (4) or *refuses* (5) for each of five self-care skills. Communication was rated as *always* (1), *most of the time* (2), *sometimes* (3), *not much* (4), or *never* (5) for several types of communication (e.g. following one step direction, written words, and sign language). Caregivers were asked to rate their child's verbal ability as *non-verbal* (1), *limited verbal* (2), *verbal* (3), or *echolalia* (4). The child's understanding of language was categorized as *does not understand* (1), *a little or some understanding* (2), *understands most or all language* (3). The numerical ratings within each category were extrapolated to the binary categories of "able" or "unable." (Table 1) If multiple

responses to a question were selected, the answer that corresponded with lower ability was entered.

Clinical Procedures

All participants were treated by a single pediatric dentist attending faculty (T.N.) or by pediatric dentistry residents under the supervision of the same attending faculty. Providers were trained how to record detailed information regarding each child's behavioral, strengths, triggers, and preferred rewards in the electronic chart. Individualized care plans included goal setting and pre-visit preparation. At each visit behavior guidance techniques such as voice control and positive reinforcement were incorporated into the desensitization program, and successive approximation to the treatment goal was applied. A description of the program framework is described elsewhere.[27]

Starting with their first desensitization visit and at each subsequent visit, child behavior was rated on a Likert scale by the dentist who performed the care (1=completely unable and 5=able without difficulty). A detailed behavioral note was also written. If behavioral data was missing, the note was reviewed by two independent raters and consensus was reached.

Numerical behavior scores for each visit were extrapolated to the Frankl behavior scale.[37] The Frankl score is a behavior rating system which separates observed behaviors into four categories ranging from definitely positive to definitely negative. (Appendix C) A positive (+) or definitely positive (+/+) Frankl score was considered cooperative. Frankl negative (-) or definitely negative (-/-) was considered uncooperative. Behavior was coded as uncooperative if the treatment goal was not achieved through voluntary cooperation or if protective stabilization was used to achieve the treatment goal. (Table 2)

Chart Abstraction and Variable Classification

A chart abstraction of the electronic health record was conducted for each child, including a detailed review of documentation for all clinical visits. We abstracted the total number of clinical visits for each patient and the number of clinical visits with a behavioral score of 3 or greater for: sitting in a dental chair and receiving a dental examination with a mouth mirror.

It was then determined if the patient was able to tolerate a "quality dental examination," defined as a behavioral score of 3 or greater for both sitting in a dental chair and receiving examination with a mouth mirror. If the patient was unable to receive a dental examination with a dental mirror during any of the treatment visits it was noted as behavioral failure. (Table 3)

Data Analysis

Descriptive statistics were calculated for all variables. Continuous variables were summarized by means and standard deviations (SD). Frequencies and percentages were calculated for categorical variables including: demographics, language, insurance, caregiver-rated ASD severity, history of behavior guidance, behavioral, communication, self-care, and mood characteristics as well as co-occurring medical conditions. Adjusted and unadjusted relative risks (RR) from modified poisson regression examined the association between ability to receive quality dental exam and all variables of interest.[38] A two-tailed statistical significance level of $p<0.05$ was used for all statistical tests.

Chapter 3: RESULTS

Sample Characteristics

The sample consisted of 168 children with a diagnosis of ASD. The male:female ratio was 4.8:1. Half identified as Caucasian and 11.3% Black/African American. Subjects were grouped according to ages 4-6 years (42.3%), 7-12 years (42.9%), and 13-18 years (14.9%). (Table 4) Approximately half were enrolled in public insurance programs and half had private insurance. Nearly all patients lived with their parents (94.6%). Caregivers reported a wide variety and frequency of comorbid conditions, the most common being sensory sensitivities (47.6%). A high percentage of patients reported history with behavioral or medical therapy for ASD (79.8%), with speech therapy being most frequently reported (74.4%). Less than a quarter of the children in the study had a previous history of protective stabilization (16.1%), sedation (19.6%), or GA (23.2%) for dental treatment. (Table 4)

Approximately 84% of caregivers provided a rating of their child's ASD severity. These ratings ranged considerably, with approximately 23% described as "mild," 40% "moderate," and 21% "severe". (Table 5) The majority were described as having social abilities such as ability to engage in shared activity or play with others. In contrast, only 36% reported having friends. About half of caregivers rated their child's level of challenging behavior as low, while the remainder described challenging behaviors as moderate or high. Only 35% of the sample was described as verbal, however nearly half understood language and the majority were capable of following one-step directions. Most children were capable of performing at least some self-care skills such as toileting, dressing, bathing, tooth brushing, and hair brushing. (Table 5)

Desensitization Intervention

It was possible to obtain a quality dental examination for 77.4% of all children within 1-2 visits; 87.5% received a quality examination by the 5th visit. It was impossible to obtain a quality dental examination for 12.5% of children. (Table 6) For those able to receive quality dental examination, the total number of visits ranged from 1 to 29 with the average being 3.5. (Table 7). The patient who attended 29 visits was able to have an exam at visit 8 and continued returning to the clinic for many more reinforcement visits (data not shown). The highest number of visits for those unable to receive a quality dental exam was 7. The elapsed time between first and last visits ranged from 0 to 34 months with the average of 8.1 for children who were able to receive a dental exam. For those who were unable to receive an exam, the elapsed time between first and last visits was shorter, ranging from 0 to 18 months. (Table 7)

Factors Associated with Ability to Receive Exam

In our analysis, the following factors were statistically significantly associated with a child's ability to tolerate dental examination: ability to be involved in group activities, verbal communication, understanding of language, mimicking/echolalia, and ability to perform self-care skills of dressing. (Table 8) Other statistically significant factors were caregiver-rated ASD severity (moderate compared to severe) and having co-morbid anxiety. Over 95% of children with ASD severity rated as mild to moderate were able to receive dental examination in contrast to only 77% of children with ASD rated as severe. Approximately 80% of children whose caregiver did not rate their ASD severity were able to receive quality dental examination.

Age, gender, child's living situation, history of protective stabilization, sedation, or GA, heightened sensory sensitivities, and level of challenging behaviors were not associated with receiving a quality dental exam. (Table 8)

Chapter 4: DISCUSSION

This prospective cohort study describes a sample of children with ASD and specific characteristics associated with the ability to receive an oral examination while sitting in a dental chair. We found that even in a population where only approximately 1/3 of patients were described as verbal with a varying degree of social and self-care abilities, the vast majority learned to receive a dental exam after 5 desensitization visits.

Clinical Context and Patients

We implemented a clinic-based program specifically designed for patients with a diagnosis of ASD. The program attempted to teach dental skills through desensitization, supportive accommodation of patient needs, and individualized reinforcement. The age and gender distribution in our sample is generally representative of the patient pool of the study clinic as well as the U.S. ASD population.[1]

As expected in a sample of children with ASD, a large proportion reported sensory sensitivities, anxiety, and sleep disorders. Similarly, the majority had previously participated in speech, occupational, behavioral, or physical therapies. These findings suggest that parents of children with ASD in our clinic had an appreciation for behavioral and medical autism therapies. Having had experience with these other non-dental therapies, families of participating children may have been more inclined than average to pursue a dental desensitization program for their child and more engaged in implementing preparatory aspects of the program. This is important to note, as caregivers' engagement with therapy is an integral component of dental desensitization programs.

Visits Required for Successful Desensitization

In this study the vast majority of patients learned to receive a dental exam as a result of enrollment in the desensitization program. While this emphasizes the fact that many children with ASD can benefit from dental desensitization, not all were successful in this treatment approach. When working with families, it may help to explain that if the child does not learn to tolerate examination within 3-5 visits it might be more practical to consider alternative behavior management approaches. While the average number of visits to obtain a quality examination was 1-2, we saw that a number of children continued returning to the clinic for many more visits. This reflects the treatment philosophy that participants benefit from reinforcing learned skills. Educational and behavioral programs to teach dental skills should factor in frequent return visits.

Factors Associated with Exam Success

We attempted to determine factors associated with children who are successfully able to undergo a quality dental exam. In previous studies, younger age,[13, 30, 36] female gender,[13] high levels of challenging behaviors,[30, 39] heightened sensory sensitivities,[33] concurrent medical diagnosis,[9, 13] and living in a group home [34] were associated with a child's inability to cooperate for dental examination. Contrary to previous studies, these factors were not associated with treatment failure in our study population. Differences in our study population and/or treatment approach may have contributed to this discrepancy.

Consistent with the findings from Marshall et al.[10], communication skills (verbal ability, understanding language), and being able to self-dress were associated with child's ability to cooperate for dental examination. Although, verbal ability was determined to be positively associated with receipt of dental care, it is important to note that approximately 2/3 of our sample

was described by their caregivers as non-verbal or having limited verbal ability. This indicates that while learning dental skills may be more likely for verbal children, good communication skills should not be a prerequisite for enrollment in a desensitization program. While not often considered to be an indication of strong verbal skills, mimicking and echolalia were positively associated with receipt of dental care. The implication is that any type of verbal ability may be associated with a greater likelihood of success. Additionally, children with social skills, such as ability to be involved in group activities, were more successful in learning to accept dental examination using the desensitization approach. Similarly, McKinney et al[7] found that children whose ASD interfered with their ability to attend school and participate in organized activities were more likely to have unmet dental needs.

The behavioral profile of a child who is successfully able to receive a quality dental examination seems consistent with a milder presentation of autism. However, our results for caregiver-rated severity were not entirely clear. That we found that children whose caregivers rated them as having moderate ASD (versus severe ASD) had a 24% increase in their ability to receive a quality dental exam. This suggests that patients who are described by their caregivers as being severely affected with ASD are less likely to tolerate an exam. Confusingly, moderate ASD severity was positively associated with successfully receiving an exam, whereas mild ASD severity was not. This may simply reflect the subjective nature of caregiver's rating or the fact that fewer children were rated as mild compared to moderate. It is also possible that the observed effect of the children rated as moderate appears larger due to random variation.

The presence of anxiety was determined to be a statistically significant factor in a child's ability to tolerate dental examination. This could indicate that children with anxiety (versus no anxiety) are truly more impacted by ASD, and as a result have greater challenges receiving care.

It is also possible that due to this study's exploratory nature and the number of tests performed; this statistically significant result was found due to error. Similarly, having no insurance was found to be statistically associated with ability to tolerate dental examination, but with such small uninsured sample (N=2) this result is not meaningful.

The population of children with autism is diverse and represents a wide variety of individual strengths and challenges. It can therefore be difficult to determine each patient's potential ability to cooperate for dental care. While each individual is unique, these findings suggest that children who are able to engage themselves socially with clinicians and caregivers and perform basic self-care are excellent candidates for desensitization . For these reasons, when discussing the possibility of dental desensitization with families, clinicians should describe the likelihood of success in terms of the child's current communication, social, and self-care abilities.

The results of this study indicate that desensitization therapy can be effective in teaching children with ASD to receive a quality dental examination. When developing a desensitization program for the dental office, practitioners should consider using a pre-visit questionnaire. Based upon our findings, a pre-visit questionnaire should include questions about the child's ASD severity (mild, moderate, or severe), number of therapies that the child is enrolled in, and questions about communication skills, language understanding, ability to participate in simple and group activities, and ability to perform self-care. Parent responses help the clinician better understand the child and may aid in predicting the child's ability to successfully learn dental skills.

Limitations

Limitations of this study include the fact that descriptions of child characteristics were based upon caregiver report. The subjective nature of the responses may have influenced the results. In addition, questionnaire responses were provided before beginning desensitization therapy, and each child's developmental trajectory over the study period was not accounted for. It is very likely that, independent of the dental desensitization treatment, some participants simply matured and acquired necessary social skills during the 36 months period. The study sample also needs to be considered. The patient population of the study clinic was predominantly enrolled in public insurance. Interestingly, a large number of study participants had private insurance, suggesting that self-selection into the desensitization program may have occurred. This may reflect the fact that many families sought out the clinic, perceiving it as unique and desirable for their child. Also, in contrast to studies that have been performed in institutional living facilities, nearly all participants in this project lived at home with their families. We may have included patients who were less profoundly affected with autism than many who reside in assisted-living facilities. Children who reside in such facilities may be more profoundly affected by their condition, and care providers may be less likely to participate in desensitization programs due to difficulty bringing children to multiple short clinical visits. For these reasons, the findings of this study may not be generalizable to the population of children with ASD as a whole.

Another important study limitation is that we did not assess the length of time that patients were able to repeat learned dental skills or whether the skills could be generalized to other practice locations. It will be important in future work to assess how well dental skills are maintained, how often they need to be reinforced through follow-up visits, and whether the

ability to receive a quality dental examination facilitates more complex treatment (e.g. sealants and fillings).

Chapter 5: CONCLUSION

1. Most children were able to receive a dental examination within 1-2 desensitization visits and a large majority (over 85%) were capable after 5 visits.
2. Greater communication skills, self-care abilities and social skills were associated with increased ability to receive dental examination after desensitization.
3. Children rated as having moderate ASD severity were more likely to receive exam than those rated as severe.

REFERENCES

1. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years. Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. 2014. "http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w".
2. Gandhi RP, Klein U. Autism spectrum disorders: an update on oral health management. J Evid Based Dent Pract 2014;14 Suppl:115-26.
3. Udhya J, Varadharaja M M, Parthiban J, Srinivasan I. Autism Disorder (AD): An Updated Review for Paediatric Dentists. J Clin Diagn Res 2014;8(2):275-9.
4. Lai B, Milano M, Roberts MW, Hooper SR. Unmet dental needs and barriers to dental care among children with autism spectrum disorders. J Autism Dev Disord 2012;42(7):1294-303.
5. Nelson LP, Getzin A, Graham D, et al. Unmet dental needs and barriers to care for children with significant special health care needs. Pediatr Dent 2011;33(1):29-36.
6. El Khatib AA, El Tekeya MM, El Tantawi MA, Omar T. Oral health status and behaviours of children with Autism Spectrum Disorder: a case-control study. Int J Paediatr Dent 2014;24(4):314-23.
7. McKinney CM, Nelson T, Scott JM, et al. Predictors of unmet dental need in children with autism spectrum disorder: results from a national sample. Acad Pediatr 2014;14(6):624-31.
8. Hernandez P, Ikkanda Z. Applied behavior analysis: behavior management of children with autism spectrum disorders in dental environments. J Am Dent Assoc 2011;142(3):281-7.
9. Marshall J, Sheller B, Williams BJ, Mancl L, Cowan C. Cooperation predictors for dental patients with autism. Pediatr Dent 2007;29(5):369-76.
10. Marshall J, Sheller B, Mancl L, Williams BJ. Parental attitudes regarding behavior guidance of dental patients with autism. Pediatr Dent 2008;30(5):400-7.
11. Germani T, Zwaigenbaum L, Bryson S, et al. Brief Report: Assessment of Early Sensory Processing in Infants at High-Risk of Autism Spectrum Disorder. J Autism Dev Disord 2014.
12. Waldman HB, Perlman SP, Wong A. Providing dental care for the patient with autism. J Calif Dent Assoc 2008;36(9):662-70.
13. LOO CY, Department of Pediatric Dentistry TUSoDM, Boston, MA, USA, GRAHAM RM, et al. Behaviour guidance in dental treatment of patients with autism spectrum disorder. International Journal of Paediatric Dentistry 2014;19(6):390-98.
14. Luscre DM, Center DB. Procedures for reducing dental fear in children with autism. J Autism Dev Disord 1996;26(5):547-56.
15. Isong IA, Rao SR, Holifield C, et al. Addressing dental fear in children with autism spectrum disorders: a randomized controlled pilot study using electronic screen media. Clin Pediatr (Phila) 2014;53(3):230-7.
16. Pilebro C, Backman B. Teaching oral hygiene to children with autism. Int J Paediatr Dent 2005;15(1):1-9.
17. Lowe O, Lindemann R. Assessment of the autistic patient's dental needs and ability to undergo dental examination. ASDC J Dent Child 1985;52(1):29-35.

18. Kuhaneck HM, Chisholm EC. Improving dental visits for individuals with autism spectrum disorders through an understanding of sensory processing. Spec Care Dentist 2012;32(6):229-33.
19. Backman B, Pilebro C. Visual pedagogy in dentistry for children with autism. ASDC J Dent Child 1999;66(5):325-31, 294.
20. Nelson TM, Sheller B, Friedman CS, Bernier R. Educational and therapeutic behavioral approaches to providing dental care for patients with Autism Spectrum Disorder. Spec Care Dentist 2015;35(3):105-13.
21. Orellana LM, Martinez-Sanchis S, Silvestre FJ. Training adults and children with an autism spectrum disorder to be compliant with a clinical dental assessment using a TEACCH-based approach. J Autism Dev Disord 2014;44(4):776-85.
22. Cuvo A, Godard A, Huckfeldt R, DeMattei R. Training Children with autism spectrum disorders to be compliant with an oral assessment. Research in Autism Spectrum Disorders 2010;4:681-96.
23. Shapiro M, Melmed RN, Sgan-Cohen HD, Parush S. Effect of sensory adaptation on anxiety of children with developmental disabilities: a new approach. Pediatr Dent 2009;31(3):222-8.
24. Fox C, Newton JT. A controlled trial of the impact of exposure to positive images of dentistry on anticipatory dental fear in children. Community Dent Oral Epidemiol 2006;34(6):455-9.
25. Lieberman S. Psychotherapy by Reciprocal Inhibition: Joseph Wolpe. Br J Psychiatry 1986;149:518-9.
26. Connick C, Pugliese S, Willette J, Palat M. Desensitization: strengths and limitations of its use in dentistry for the patient with severe and profound mental retardation. ASDC J Dent Child 2000;67(4):250-5.
27. Nelson TM, Sheller B, Friedman CS, Bernier R. Educational and therapeutic behavioral approaches to providing dental care for patients with Autism Spectrum Disorder. Spec Care Dentist 2014.
28. Wood JJ, Drahota A, Sze K, et al. Cognitive behavioral therapy for anxiety in children with autism spectrum disorders: a randomized, controlled trial. J Child Psychol Psychiatry 2009;50(3):224-34.
29. Tesini Nancy Lurie Marks Family Foundation - "D-Termined Program of Repetitive Tasking and Familiarization in Dentistry". 2011. "http://www.nlmfoundation.org/media/clips/dental/dental_medium_clip1.htm".
30. Du RY, Yiu CC, Wong VC, McGrath CP. Autism Developmental Profiles and Cooperation with Oral Health Screening. J Autism Dev Disord 2015.
31. Loo CY, Graham RM, Hughes CV. Behaviour guidance in dental treatment of patients with autism spectrum disorder. Int J Paediatr Dent 2009;19(6):390-8.
32. GG D, EF P, E V, JT S. Evaluation of the efficacy of a dental plaque control program in autistic patients: J Autism Dev Disord; 2010. p. 704-8.
33. Stein LI, Polido JC, Cermak SA. Oral care and sensory over-responsivity in children with autism spectrum disorders. Pediatr Dent 2013;35(3):230-5.
34. J K, AJ N. Characteristics of patients with autistic disorder (AD) presenting for dental treatment. A survey and chart review.; 1999. p. 200-07.
35. Klein U, Nowak AJ. Characteristics of patients with autistic disorder (AD) presenting for dental treatment: a survey and chart review. Spec Care Dentist 1999;19(5):200-7.

36. Dias GG, Prado EF, Vadasz E, Siqueira JT. Evaluation of the efficacy of a dental plaque control program in autistic patients. J Autism Dev Disord 2010;40(6):704-8.
37. Frankl SN, Shiere FR, Fozels HR. Should the parent remain with the child in the dental operatory? J Dent Child 1962;29:150-63.
38. Zou G. A modified poisson regression approach to prospective studies with binary data. Am J Epidemiol 2004;159(7):702-6.
39. Kokina A, Kern L. Social Story interventions for students with autism spectrum disorders: a meta-analysis. J Autism Dev Disord 2010;40(7):812-26.

Table 1. Categorization of Patient Behavioral Characteristics Based Upon Caregiver Responses

Behavioral Characteristics	**Caregivers' Numerical Ratings**	**Corresponding Value**	
		Able	**Unable**
Social skills	(1)Not able; (2)Sometimes able; (3)Infrequently able; (4)frequently able; (5)Able all the time	3,4,5	1,2
Self-care abilities	(1)Totally independent; (2)Needs verbal coaching/prompting; (3)Needs occasional help; (4)Totally dependent; (5)Refuses	1,2,3	4,5
Communication	(1)Always; (2)Most of the time; (3)Sometimes; (4)Not much; (5)Never	1,2	3,4,5
Verbal ability	(1)Non-verbal; (2)Limited verbal; (3)Verbal; (4)Echolalia	3	1,2,4
Language understanding	(1)Does not understand; (2)A little or some understanding; (3)Understands most or all language	3	1,2

Table 2. Behavioral Rating System at Dental Visits

Likert Scale	Description	Corresponding Frankl Score	What it means
1	Completely unable	-/-	Uncooperative
2	Able with extreme difficulty	-	
3	Able with moderate difficulty	+	Cooperative
4	Able with minimal difficulty	+/+	
5	Able without difficulty	+/+	

Table 3. Categorization of Abilities at Treatment Visits

<table>
<tr><th colspan="2">Procedure</th><th>Behavioral Score</th><th>Description</th></tr>
<tr><td colspan="2" rowspan="2">Sitting in the dental chair</td><td>1, 2</td><td>Unable</td></tr>
<tr><td>3, 4, 5</td><td>Able</td></tr>
<tr><td colspan="2" rowspan="2">Receiving dental examination with a mouth mirror</td><td>1, 2</td><td>Unable</td></tr>
<tr><td>3, 4, 5</td><td>Able</td></tr>
<tr><td rowspan="3">Quality dental examination:</td><td>Sitting in dental chair
AND
Receive dental examination with mouth mirror</td><td>3, 4, 5
AND
3, 4, 5</td><td>Able</td></tr>
<tr><td>Sitting in dental chair
AND
Receive dental examination with mouth mirror</td><td>1,2
AND
1,2, 3, 4, 5</td><td>Unable</td></tr>
<tr><td>Sitting in dental chair
AND
Receive dental examination with mouth mirror</td><td>1,2, 3, 4, 5
AND
1,2</td><td>Unable</td></tr>
</table>

Table 4. Demographics and Treatment Variables for Children with ASD

	Total (N = 168) N (%)	**Was the Child Able to Receive Quality Dental Examination?**	
		Yes (N= 147) N (%)	**No (N= 21) N (%)**
Demographic			
Age			
4-6 years	71 (42.3)	60 (40.8)	11 (52.4)
7-12 years	72 (42.9)	63 (42.9)	9 (42.9)
13-18 years	25 (14.9)	24 (16.3)	1 (4.8)
Gender			
Male	139 (82.7)	120 (81.6)	19 (90.5)
Female	29 (17.3)	27 (18.4)	2 (9.5)
Race			
Caucasian	85 (50.6)	74 (50.3)	11 (52.4)
Asian	16 (9.5)	16 (10.9)	3 (14.3)
Black/African American	19 (11.3)	15 (10.2)	1 (4.8)
Other/Multiple	28 (16.7)	25 (17.0)	3 (14.3)
Unanswered	20 (11.9)	17 (11.6)	3 (14.3)
Insurance			
Public	87 (51.8)	77 (52.4)	10 (47.6)
Private	79 (47.0)	68 (46.3)	11 (52.4)
None	2 (1.2)	2 (1.4)	0 (0.0)
Lives With			
Parents	159 (94.6)	140 (95.2)	19 (90.5)
Other	5 (3.0)	4 (2.7)	1 (4.8)
Unanswered	4(2.4)	3 (2.0)	1 (4.8)
Co-Morbid Medical Condition Variables			
The presence of any:			
Sensory Sensitivities	80 (47.6)	70 (47.6)	10 (47.6)
Anxiety	51 (30.4)	48 (32.7)	3 (14.3)
Sleep Disorder	41 (24.4)	34 (23.1)	7 (33.3)
Gastro-Intestinal Problems	31 (18.5)	24 (16.3)	7 (33.3)
Seizures	13 (7.7)	11 (7.5)	2 (9.5)
History of Therapy Variables			
Previous history of any:			
Therapy	134 (79.8)	118 (80.3)	16 (76.2)
Speech Therapy	125 (74.4)	109 (74.1)	16 (76.2)
Occupational Therapy	98 (58.3)	88 (59.9)	10 (47.6)
Complementary and Alternative Medicine	83 (49.4)	70 (47.6)	13 (61.9)
Behavioral Therapy	79 (47.0)	70 (47.6)	9 (42.9)
Physical Therapy	38 (22.6)	30 (20.4)	8 (38.1)

Number of Therapies Child Receives			
0-1	35 (20.8)	29 (19.7)	6 (28.6)
2-3	59 (35.1)	56 (38.1)	3 (14.3)
4-5	45 (26.8)	36 (24.5)	9 (42.9)
6+	21 (12.5)	18 (12.2)	3 (14.3)
Unknown	8 (4.8)	8 (5.4)	0 (0.0)
History of Behavior Guidance Variables			
Previous history of any:			
Protective Stabilization	27 (16.1)	23 (15.6)	4 (19.0)
Sedation	33 (19.6)	28 (19.0)	5 (23.8)
General Anesthesia	39 (23.2)	32 (21.8)	7 (33.3)

Table 5. Behavioral Characteristics of Children with ASD

	Total (N = 168) N (%)	Was the Child Able to Receive Quality Dental Examination?	
		Yes (N= 147) N (%)	No (N= 21) N (%)
Caregiver-rated ASD Severity			
Mild	38 (22.6)	33 (22.4)	5 (23.8)
Moderate	68 (40.5)	65 (44.2)	3 (14.3)
Severe	35 (20.8)	27 (18.4)	8 (38.1)
Don't Know	27 (16.1)	22 (15.0)	5 (23.8)
Level of Challenging Behaviors			
Low	81 (48.2)	72 (49.0)	9 (42.9)
Moderate	71 (42.3)	62 (42.2)	9 (42.9)
High	13 (7.7)	11 (7.5)	2 (9.5)
Unknown	3 (1.8)	2 (1.4)	1 (4.8)
Social Abilities			
Any ability to:			
Cooperate during Simple Activities	144 (85.7)	131 (89.1)	13 (61.9)
Be Involved in Group Activities	103 (61.3)	96 (65.3)	7 (33.3)
Engage in Shared Activities	147 (87.5)	131 (89.1)	16 (76.2)
Play with Others	99 (58.9)	91 (61.9)	8 (38.1)
Have Friends	60 (35.7)	55 (37.4)	5 (23.8)
Communication Skills			
Any ability to:			
Be Verbal	59 (35.1)	57 (38.8)	2 (9.5)
Understand Language	79 (47.0)	74 (50.3)	5 (23.8)
Follow One-step Directions	115 (68.5)	104 (70.7)	11 (52.4)
Mimic (Echolalia)	26 (15.5)	26 (17.7)	0 (0.0)
Communicate with Written Words	18 (10.7)	17 (11.6)	1 (4.8)
Use Sign Language	4 (2.4)	4 (2.7)	0 (0.0)
Self-Care Skills			
Able to:			
Dress by Self	134 (79.8)	122 (83.0)	12 (57.1)
Use Toilet by Self	143 (85.1)	129 (87.8)	14 (66.7)
Bathe by Self	105 (62.5)	96 (65.3)	9 (42.9)
Brush Own Teeth	99 (58.9)	90 (61.2)	9 (42.9)
Brush Own Hair	96 (57.1)	87 (59.2)	9 (42.9)

Table 6. Number of Visits Required to Obtain Quality Dental Examination By Age

Age	**1-2 N (%)**	**3-5 N (%)**	**>5 N (%)**	**Unable N (%)**	**Total N (%)**	**P-value**
4-6 years	53 (74.6)	4 (5.6)	3 (4.2)	11 (15.5)	71	0.429
7-12 years	57 (79.2)	5 (6.9)	1 (1.4)	9 (12.5)	72	
13-18 years	20 (80.0)	4 (16.0)	0 (0.0)	1 (4.0)	25	
Total	130 (77.4)	13 (7.7)	4 (2.4)	21 (12.5)	168	

Table 7. Clinical Visits Required to Obtain Quality Dental Examination

	Able to Receive Quality Dental Exam (N = 147)	**Unable to Receive Quality Dental Exam (N = 21)**
	Mean (SD*) [minimum, maximum]	Mean (SD*) [minimum, maximum]
Total Number of Visits to Clinic	3.5 (3.3) [1, 29]	3.3 (1.98) [1, 7]
Number of Visits Until Quality Dental Examination was Obtained	1.6 (1.4) [1, 11]	--
Length of Time between First and Last Visit (months)	8.1 (7.9) [0, 34.2]	4.5 (5.3) [0, 18.4]
Number of Visits Required to Obtain a Quality Dental Examination	**N (%)**	
1	101 (60.1)	
2	29(17.3)	
3	10 (6.0)	
4	1 (0.6)	
5+	6 (3.6)	
Unable	21 (12.5)	
Total	168 (100)	

*SD = Standard Deviation

Table 8: Estimated Associations between Predictors and the Ability to Receive Quality Dental Examination

	Unadjusted RR	95% CI	P-Value
Demographic			
Age			0.11
4-6 years	0.88	(0.77, 1.00)	0.51
7-12 years	0.91	(0.81, 1.03)	0.13
13-18 years	reference		
Gender			0.22
Male	Reference		
Female	1.08	(0.96, 1.22)	
Lives With			0.67
Parents	Reference		
Other	0.91	(0.58, 1.42)	
Insurance			<0.001
Private	0.97	(0.87, 1.09)	0.64
Public	Reference		
None	1.13	(1.05, 1.22)	0.002
Caregiver-rated ASD Severity			0.04
Mild	1.13	(0.9, 1.40)	0.29
Moderate	1.24	(1.03, 1.50)	0.03
Severe	Reference		
History of Behavior Guidance			
Any history of:			
Protective Stabilization			0.69
Yes	0.97	(0.81, 1.15)	
No	Reference		
Sedation			0.60
Yes	0.96	(0.82, 1.12)	
No	Reference		
General Anesthesia			0.27
Yes	0.91	(0.78, 1.07)	
No	Reference		
Medical			
Any history of receiving:			
Any type of Therapies			0.66
Yes	1.04	(0.87, 1.24)	
No	Reference		
Behavioral Therapy			0.32
Yes	1.08	(0.93, 1.26)	
No	Reference		
Physical Therapy			0.14
Yes	0.87	(0.73, 1.04)	

No	Reference		
Speech Therapy			0.64
Yes	1.05	(0.86, 1.27)	
No	Reference		
Occupational Therapy			0.26
Yes	1.10	(0.93, 1.30)	
No	Reference		
Complementary Alternative Medicine (CAM)			0.97
Yes	1.00	(0.86, 1.16)	
No	Reference		
Number of Therapies Child Receives			0.08
0-1	Reference		
2-3	1.15	(0.97, 1.35)	0.10
4-5	0.97	(0.78, 1.19)	0.74
6+	1.03	(0.82, 1.30)	0.74
Co-Morbid Medical Conditions			
Any history of:			
Gastro-Intestinal Problems			0.14
Yes	0.86	(0.71, 1.05)	
No	Reference		
Seizures			0.77
Yes	0.96	(0.76, 1.23)	
No	Reference		
Sleep Disorders			0.36
Yes	0.93	(0.80, 1.09)	
No	Reference		
Sensory Sensitivities			>0.99
Yes	1.00	(0.89, 1.12)	
No	Reference		
Anxiety			0.04
Yes	1.11	(1.00, 1.23)	
No	Reference		
Social Ability			
Any ability to:			
Cooperate during Simple Activities			0.06
Yes	1.31	(0.99, 1.72)	
No	Reference		
Be Involved in Group Activities			0.02
Yes	1.18	(1.02, 1.35)	
No	Reference		
Engage in Shared Activities			0.35
Yes	1.11	(0.89, 1.40)	
No	Reference		
Play with Others			0.08

Yes	1.12	(0.99, 1.26)	
No	Reference		
Have Friends			0.21
Yes	1.07	(0.96, 1.20)	
No	Reference		
Level of Challenging Behaviors			0.90
Low	Reference		
Moderate	0.98	(0.87, 1.11)	0.77
High	0.95	(0.75, 1.22)	0.69
Communication Skill			
Any ability to:			
Be Verbal			0.002
Yes	1.17	(1.06, 1.29)	
No	Reference		
Understand Language			0.02
Yes	1.14	(1.02, 1.28)	
No	Reference		
Follow One-step Directions			0.1
Yes	1.14	(0.98, 1.34)	
No	Reference		
Mimic (Echolalia)			<0.001
Yes	1.18	(1.10, 1.26)	
No	Reference		
Communicate with Written Words			0.15
Yes	1.10	(0.96, 1.25)	
No	Reference		
Self-Care Skill			
Able to:			
Dress by Self			0.04
Yes	1.27	(1.01, 1.58)	
No	Reference		
Use Toilet by Self			0.08
Yes	1.25	(0.97, 1.61)	
No	Reference		
Bathe by Self			0.07
Yes	1.13	(0.99, 1.30)	
No	Reference		
Brush Own Teeth			0.13
Yes	1.10	(0.97, 1.25)	
No	Reference		
Brush Own Hair			
Yes	1.11	(0.97, 1.27)	0.12
No	Reference		

Appendix A: Summary of Previous Studies

Study	Total (N)	Design	Primary results
Marshall et al[9]	108	Prospective, descriptive study, measuring 26 possible predictors of cooperation. Frankl behavior ratings was used to evaluate behavior during different appointment type (e.g. emergency visit, initial and recall examination, radiographs, and operative visit): (++)(+) = cooperative (--)(-) = uncooperative	The following variables predict uncooperative behavior: - Nonverbal/echolalia - Cannot do multi-step instruction - Cannot read at age 6 - Special education classroom - Not toilet trained - Cannot do independent tooth brushing - Concurrent diagnosis with developmental delay/ mental retardation Other outcome: Parents are able to predict accurately their child's ability to sit in chair and tolerate dental prophylaxis but overestimates on their ability to obtain radiographs.
Backman et al[19]	16	Prospective study using visual pedagogy to desensitize a child with autism to the steps of dental examination in multiple 15-20 minutes visits over 1.5 year. The following categories were used to evaluate a child's behavior: -Full cooperation -Reluctant cooperation -No cooperation	- The average number of visits to clinic is 10 (between 4-25 visits). - There is a longer interval between "no" and "reluctant" cooperation than between "reluctant" to "full" cooperation. - No cooperation predictors was analyzed
Loo et al[13]	ASD group (395) and non-	Retrospective and descriptive study to evaluate variables associated with cooperation of a child with ASD compared to an	The following variables predict uncooperative behavior: - Younger age (1year increase in age = 8% decrease in uncooperation) - Gender (female is more likely to need GA)

	ASD group (386)	otherwise healthy child in a dental setting. Frankl behavior ratings was used to evaluate behavior at every dental visit: (++)(+) = cooperative (--)(-) = uncooperative	- ASD diagnosis - Presence of additional diagnosis The following variables were inconclusive: - Residency in group home - Presence of seizure disorder - History of restorative/surgical treatment = increase uncooperative behavior for healthy pt.
Stein et al[33]	ASD group (196) and non-ASD group (202)	Survey of parents' report of their child's uncooperative behaviors in home and dental office to investigate the relationship between 8 sensory sensitivities (touch, oral, taste, smell, sound, vibration, movement, and light) and oral care difficulties between a child with ASD and typically developing child. Five-point Likert scale was used to evaluate child's behavior (not at all difficult to extremely difficult).	The following variables predict uncooperative behavior: - Parents report of child's sensory over-responsivity (moderate-to-extreme oversensitivity to three or more of the 8 sensory modalities). - Diagnosis of ASD increases the magnitude of sensory over responsivity compared to typically developing children.
Du et al[30]	347	A prospective study to determine the association of child's ASD developmental levels and cooperation to an oral health screening in the child's classroom with a built-in LED light mirror.	The following variables predict uncooperative behavior: - Younger age - Reduced cognitive function = five-fold likelihood of inability to cooperate. - High level of challenging behaviors (harmful and potentially life-threatening) = tenfold likelihood of inability cooperate
Dias et al[36]	38	Prospective study to evaluate participation and effectiveness of plaque control prevention program over 180 days in patients with ASD.	The following variables are associated with improvements in oral hygiene: - Younger age - Caregiver report of cooperation - Family income of minimum wage = lowest effectiveness rate.

		Caregivers report cooperation level as: cooperative and non-cooperative. *Pt that is unable to tolerate clinical examination is excluded from the study.	
Pilebro et al[16]	14	Prospective study to evaluate oral hygiene improvements: reduction in plaque level, oral hygiene habit after 18 months using visual pedagogy.	Inconclusive cooperative predictors due to the small number of children in the study. However, it showed that visual pedagogy is a suitable method to teach children with autism oral hygiene.
Lowe et al[17]	ASD group (20) Non-ASD group (20)	Prospective study to evaluate success in utilizing certain BGTs. Success is defined as the ability to tolerate comprehensive extra-oral and intra-oral examination with fingers and an explorer as well as the ability to obtain clinically acceptable bitewing radiographs	- 50% of patients with ASD tolerated examination and bitewing radiographs - Positive reinforcement, TSD, and utilizing negative reinforcement when necessary are found to aid in success. - No conclusive cooperative predictors
Isong et al[15]	80	Pilot RCT study to determine if electronic screen media strategies are effective and effective and practical for reducing fear and increasing compliance. Venham behavior Rating scale was used to measure the level of anxiety of patient at the end of dental visit (0=cooperative; 5=uncooperative)	- Inconclusive due to small sample - Electronic screen media could potentially reduce uncooperative behaviors in children during dental procedures.
Orellana et al[21]	72	Prospective study to evaluate the effectiveness of a psychoeducational training	- TEACCH program works as a way to desensitize children with ASD to a dental examination process - the improvement was not influenced by level of cognitive development * This study didn't account for patient's sensory profile of each patient.

		(TEACCH) program in facilitating oral assessment. Success is defined as the ability to complete 10 consecutive steps of oral assessment after five training sessions. Frankl behavior ratings was used to evaluate behavior for each step. (++)(+) = cooperative (--)(-) = uncooperative	*This study also didn't take place in a dental clinic but in an already familiar autism center and school that they are currently enrolled in.
Klein et al [35]	43	Retrospective and descriptive study to analyze techniques of behavior management and level of cooperation. Frankl behavior ratings was used to evaluate behavior at their first appointment. (++)(+) = cooperative (--)(-) = uncooperative	The following variables correlate to uncooperative behavior: - patients living in group home - high caries activity Other finding: age is not associated with exhibited behavior

Appendix B: Pre-Visit Questionnaire

CPD Autism Clinic

New Patient Interview

MR#
_____
Reviewed By

Date_____

Your Child's Name_____ **Date of Birth**_____

Age_____ **Gender**_____

Race_____ **Language**_____

Who referred you to us?

_____

Who is your Child's Primary Care Doctor?

_____ ☐ Do not have one

Who does your child live with?

_____

Who will usually bring your child to the dental visits?

_____

Where does your child go to school?

_____

Does your child have an Individualized Educational Program (IEP)?

☐ Yes ☐No

Questions about your child's medical history

1. Has your child been diagnosed with an Autism Spectrum Disorder (ASD)?

☐ Yes

☐ No → Skip to question #4

☐ Unsure

2. What type of Autism Spectrum Disorder does your child have?

☐ Autism/Autistic Disorder

☐ Asperger's

☐ Pervasive Developmental Disorder-Not Otherwise specified (PDD-NOS)

☐ Don't Know

☐ Other, please specify: _____

3. Would you describe your child's ASD as:

☐ Mild

☐ Moderate

☐ Severe

☐ Don't Know

4. Is your child currently receiving any treatment/therapies for Autism Spectrum Disorder?

☐ Yes

☐ No → Skip to question #5

☐ Don't know

5. What types of treatment or therapy(s) is your child currently receiving?

MARK (X) TO ALL THAT APPLY

Is your child receiving:	Yes	No
Any Medications	☐	☐
Behavioral Therapy		
Applied Behavioral Analysis (ABA)	☐	☐
Developmental, Individual Differences, Relationship based approach (DIR)	☐	☐
Other, describe:	☐	☐
Physical Therapy	☐	☐

Speech Therapy	☐	☐
Occupational Therapy	☐	☐
Complementary Alternative Medicine		
Special Diet	☐	☐
Supplements	☐	☐
Vitamins	☐	☐
Acupuncture	☐	☐
Other types of Eastern medicine	☐	☐
Chelation Therapy	☐	☐
Anything else? (LIST BELOW) :	☐	☐

6. Does your child have additional medical conditions?

☐ None

☐ Yes (MARK (X) ALL THAT APPLY)

☐ Seizures

☐ Sleep problem

☐ Stomach or gastro-intestinal problems

☐ Sensory Problems

☐ Anxiety/Depression

☐ Oral/feeding problems (Please list):

_____

☐ Other behavioral Issues (Please list):

_____

☐ Other (Please list):

_____

7. Please list your child's medications:

_____

_____

_____

_____

_____

****YOU MAY INCLUDE A SEPARATE WRITTEN LIST IF THAT IS SIMPLER OR THERE IS A LARGE LIST****

8. Does your child have any allergies? ☐Yes→Please List below ☐No

_____

_____

_____

Questions about your child's behavior and social abilities

1. How would you describe your child's reading level?

☐ Does not read (Low)

☐ Some skills but not fluent (Limited)

☐ Fluent reader (Average/High)

☐ Don't know

☐ Not Applicable (<5 yrs old)

2. What is your child 's communication ability?

☐ Non-verbal

☐ Limited Verbal

☐ Verbal

☐ Mimicking (Echolalia)

3. How would you describe your child 's understanding of language?

☐ Does not understand

☐ A little or some understanding

☐ Understands most or all language

☐ Other (please describe): _____

4. How would you describe your child 's level of challenging behaviors?

☐ Typically engages in minimally challenging behaviors (Low)

☐ Typically engages in disruptive behaviors (Moderate)

☐ Typically engages in dangerous behaviors (High)

5. How would you describe the typical frequency of your child 's challenging behaviors?

☐<1 per day ☐1-2 per day ☐3+ times per day ☐never

6. Please rate your child's ability to *take part* in the following

	Not Able	Infrequently Able	Sometimes Able	Frequently Able	Able all the Time
Involve him/herself in group activities given the opportunity	☐	☐	☐	☐	☐
Engage with you in shared activity (Joint attention)	☐	☐	☐	☐	☐
Read Stories with you (caregiver/parent)	☐	☐	☐	☐	☐
Cooperate during simple activities (for example, dining with the family, grocery shopping, etc.)	☐	☐	☐	☐	☐

Having Friends	☐	☐	☐	☐	☐
Playing with Others	☐	☐	☐	☐	☐

7. Please rate your child's ability to do these self-care skills.

	Totally Independent	**Needs Verbal coaching/prompting**	**Needs Occasional help**	**Totally Dependent**	**Refuses**
Toileting	☐	☐	☐	☐	☐
Tooth Brushing	☐	☐	☐	☐	☐
Bathing	☐	☐	☐	☐	☐

Dressing	☐	☐	☐	☐	☐
Hair brushing	☐	☐	☐	☐	☐

8. How often are your child's teeth brushed?

Less than once per week	Once or twice a week	3-6 times/week	Once a day	More than once a day
☐	☐	☐	☐	☐

9. Are you or your child able to floss their teeth? ☐ Yes ☐No → Skip to question #10

If yes, how often are your child's teeth flossed?

Less than once per week	Once or twice a week	3-6 times/week	Once a day	More than once a day
☐	☐	☐	☐	☐

10. How does your child communicate?

Does Your Child:

	Always	Most of the time	Sometimes	Not Much	Never
Follow one-step directions	☐	☐	☐	☐	☐
Use sign language	☐	☐	☐	☐	☐
Use PECS (Pictures)	☐	☐	☐	☐	☐
Communicate using written words (Computer/Pen/Paper)	☐	☐	☐	☐	☐
Use gestures or lead you to his/her needs/wants	☐	☐	☐	☐	☐

Have vocalizations that indicate his/her moods	☐	☐	☐	☐	☐

11. What else should we know about your child in terms of communicating?

_____

_____

12. In general what is your child 's mood like?

	Always	**Most of the time**	**Sometimes**	**Not Much**	**Never**
Happy	☐	☐	☐	☐	☐
Calm	☐	☐	☐	☐	☐
Hyperactive	☐	☐	☐	☐	☐
Tense/Anxious	☐	☐	☐	☐	☐

Agitated	☐	☐	☐	☐	☐
Sad	☐	☐	☐	☐	☐
Self Injurious	☐	☐	☐	☐	☐
Extreme highs/lows	☐	☐	☐	☐	☐
Aggressive	☐	☐	☐	☐	☐
Other					
(please describe)	☐	☐	☐	☐	☐

13. What are common things or 'triggers' that make your child's behavior get worse?

	Yes	No
Loud Noises	☐	☐
Bright Lights	☐	☐
Unfamiliar Smells	☐	☐
Unfamiliar Tastes	☐	☐

Misunderstanding communication	☐	☐
Other, specify:	☐	☐

Is there any additional information about triggers you think would be helpful to the dentist?

14. What do you do to help calm your child when he/she is upset?

15. When your child becomes distracted, what tends to help him/her focus? What brings him/her back?

16. What are your child's interests? For example, does your child engage with animals, toys, video games, movies, music? What kinds are his/her favorite?

17. What are your child's strengths?

18. What motivates your child or will serve as a good reward for positive behavior at the dentist?

	Yes	No
Ipad/videogame time	☐	☐
Prize/trinket from dentist	☐	☐
Special food or meal	☐	☐
Special outing	☐	☐
Toy purchased by family	☐	☐
Other, specify:		

19. What else should we know about your child 's behavior?

_____

_____

_____

_____

Questions about your child's history of dental treatment

1. Has your child ever seen a dentist?

☐ Yes

☐ No → Skip to question #4

2. In the past 12 months, how many times did your child see a dentist?

_____ times ☐ Don't know

3. **In the past 12 months did your child receive preventive dental care, such as check-ups or dental cleanings from a dentist?**

☐ Yes ☐ No ☐ Don't Know

4. **In the past 12 months did your child receive dental care for a problem like cavities or an injured or cracked tooth?**

☐ Yes ☐ No ☐ Don't Know

5. **In the past 12 months, did your child receive all the dental care he/she needed?**

☐ Yes ☐ No ☐ Don't Know

6. **Think about your child's last dental visit. How well do you feel the visit went?**

☐ Poorly ☐ Fair ☐ Good ☐ Excellent ☐ Don't know

7. **What was the reason for your child's last dental visit?**

_____

8. **At your child's last dentist visit, what was your child's level of stress?**

☐Low ☐Medium ☐High ☐Very high ☐ Don't know

9. **At your child's last dentist visit, what was your level of stress?**

☐Low ☐Medium ☐High ☐Very high ☐ Was not there

10. **At your child's last dentist visit, what key things affected their stress level?**

_____

_____

_____

11. **At your child's last dentist visit, what key things affected your stress level?**

_____

_____

_____

12. **At your child's last dentist visit, what kind of dentist did your child see?**

☐General dentist ☐Pediatric dentist ☐ Don't know

13. Does your child have any oral habits? (chewing on things, mouthing non-food items, grinding teeth, etc.) ☐ Yes ☐ No ☐ Don't Know

14. Has your child ever had any of the following during a dental visit?

a. Papoose board (immobilization wrap/restraint)

☐ Yes ☐ No ☐ Don't Know

b. Sedation (calming medication)

☐ Yes ☐ No ☐ Don't Know

c. General anesthesia (loss of consciousness as during surgery)

☐ Yes ☐ No ☐ Don't Know

15. Think about your child 's last visit with the dentist. If your child has not been to the dentist think about how difficult the following experiences would be for them.

Please rate your child 's degree of difficulty with the following experiences.

	Very Easy/No Difficulty	Somewhat Easy	Somewhat Difficult	Very Difficult	Unsure/Not Applicable
Waiting in the reception area for more than 5 minutes	☐	☐	☐	☐	☐

Moving to the exam room area from the waiting room	☐	☐	☐	☐	☐
Sitting in the dental chair	☐	☐	☐	☐	☐
Staying still for the exam	☐	☐	☐	☐	☐
Having his/her tooth cleaning	☐	☐	☐	☐	☐
Having x-rays	☐	☐	☐	☐	☐
Having fluoride brushed on their teeth	☐	☐	☐	☐	☐
Having a cavity filled	☐	☐	☐	☐	☐
Having an injection or invasive type of treatment (extraction, filling, crown, etc.)	☐	☐	☐	☐	☐

16. Does your child have any oral habits? (chewing on non-food items, picking, thumb sucking, lip smacking, etc.) ☐ Yes → Please Explain ☐ No ☐ Don't Know

_____

_____

_____

17. **Has your child ever had any injuries to their teeth?**

☐ Yes → Please Explain ☐ No ☐ Don't Know

_____

_____

_____

18. Is there anything else you would want us to know about your child 's dental experiences?

_____

_____

_____

19. The following is a list of treatments. Which would you like us to provide?

Routine Exam	☐ Yes	☐ No	☐ Don't Know
Cleaning	☐ Yes	☐ No	☐ Don't Know

Filling or Crown	☐ Yes	☐ No	☐ Don't Know
A lot of Work	☐ Yes	☐ No	☐ Don't Know
An Extraction	☐ Yes	☐ No	☐ Don't Know
Orthodontic Treatment	☐ Yes	☐ No	☐ Don't Know
Not sure, seems to be in pain	☐ Yes	☐ No	☐ Don't Know
Don't Know	☐ Yes	☐ No	☐ Don't Know
Other (please explain)			

20. Would you like the dentist to treat your child using the following?

Gradual desensitization and behavioral modification approach	☐ Yes	☐ No	☐ Don't Know
Sedation	☐ Yes	☐ No	☐ Don't Know
Restraint/Protective Stabilization	☐ Yes	☐ No	☐ Don't Know

General Anesthesia/Operating Room	☐ Yes	☐ No	☐ Don't Know
Don't Know	☐ Yes	☐ No	☐ Don't Know
Other (please describe)	☐ Yes	☐ No	☐ Don't Know

21. Which of the following would be your preferred treatment choice?

(please rank your preferences, 1 being your first choice)

☐ Gradual introduction to dental office/procedures

☐ Sedation

☐ Restraint / protective stabilization

☐ General Anesthesia / operating room

☐ Don't know

☐Other, describe:_____

Thank you for completing this form. The information will be used to help your child with dental treatment.

Appendix C: Frankl Behavioral Rating Scale

-/-	Definitely negative. Refusal of treatment, forceful crying, fearfulness, or any other overt evidence of extreme negativism.
-	Negative. Reluctance to accept treatment, uncooperative, some evidence of negative attitude but not pronounced (sullen, withdrawn).
+	Positive. Acceptance of treatmnet; cautious behavior at times; willingness to comply with the dentist, at times with reservation, but patient follows the dentist's direction cooperatively.
+/+	Definitely positive. Good rapport with the dentist, interest in the dental procedures, laughter and enjoyment.