

**UNMET DENTAL NEEDS AND BARRIERS TO DENTAL CARE AMONG CHILDREN
WITH AUTISM SPECTRUM DISORDERS**

Bien Lai (BDS)

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Approved by:

Michael Milano, DMD

Michael Roberts, DDS, MScD

Stephen Hooper, Ph.D.

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ABSTRACT

BIEN LAI: Unmet Dental Needs and Barriers to Dental Care among Children with Autism Spectrum Disorder

(Under the direction of Michael Milano, Michael Roberts and Stephen Hooper)

The purpose of this study is to examine the unmet dental needs and barriers to dental care among children with Autism Spectrum Disorder (ASD) in North Carolina. Mail-in pilot-tested questionnaires were sent to a stratified random sample of 1500 families from the North Carolina Autism Registry. Multivariate logistic regression analysis was used to determine the significance of unmet dental needs and other predictors. Of the 568 surveys returned (RR=38%), 555 were complete and used. Sixty-five (12%) children had unmet dental needs. Of 516 children (93%) who had been to a dentist, 11% still reported unmet needs. The main barriers to dental care were child's behavior, cost, and lack of insurance. The significant predictor variables of unmet needs were child's behavior ($P=.01$), child's dental health ($P<.001$), and caregiver's last dental visit greater than 6 months ($P=.002$). Type of ASD did not have an effect on having unmet dental needs.

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LIST OF ABBREVIATIONS

ADDM: Autism Development and Disability Monitoring

ADHD: Attention Deficit Hyperactivity Disorder

ASD: Autism Spectrum Disorder

CI: Confidence Interval

CIDD: Carolina Institute for Developmental Disabilities

CDL: Clinical Center for the study of Development and Learning

CSHCN: Children with Special Health Care Needs

NCTraCS: North Carolina Translational and Clinical Research Institute

NHIS: National Health Interview Survey

NICHHD: National Institute of Child Health and Human Development

OR: Odds ratio

PDD-NOS: Pervasive Developmental Disorder – Not Otherwise Specified

SAS: Statistical Analysis Systems

SD: Standard Deviation

TEACCH: Treatment and Education of Autistic and Related Communication Handicapped Children

VIF: Variance Inflation Factor

INTRODUCTION

Background and prevalence

Autism spectrum disorders (ASD) is a group of disorders with a wide range of severity, characterized by impairments in language, social interaction, and a markedly restricted repertoire of activities and interests. In the psychiatric nomenclature, the spectrum, consisting of autistic disorder, Asperger's disorder and pervasive developmental disorder – not otherwise specified (PDD-NOS), is grouped under the broad category of pervasive developmental disorders, which also include 2 other conditions – Rett's disorder and childhood disintegrative disorder. (1)

People with autistic disorder are on the more severe end of the autism spectrum distribution, with an onset prior to age 3. Individuals display social awkwardness, resist changes and present with unusual stereotypic behaviors and interests. Comprehension, non-verbal and verbal languages may be affected to different degrees. Presentation ranges from totally non-verbal to poorly-articulated or delayed speech, to well-spoken sentences with an abnormal tinge or echolalia. (1-3)

Individuals with Asperger's disorder manifest milder symptoms of autistic disorder and are generally high-functioning. They do not display significant language delay or disturbance in cognitive development, and are also capable of acquiring age-appropriate self-help skills and adaptive behavior (other than in social interaction).(3)

PDD-NOS typically includes those individuals whose criteria are not met for a specific pervasive developmental disorder or other psychiatric disorders, such as “atypical autism”, which

is autism with a late age of onset or atypical symptoms. Individuals with PDD-NOS are less severely affected than those with autistic disorder.(3)

The prevalence of ASD has been increasing over the past few decades. As far back as the 1970s, autism was believed to occur in 4 to 5 per 10,000 children, translating to a prevalence of 0.04-0.05%. (4, 5) Currently, data from the Autism Development and Disability Monitoring (ADDM) Network estimates that the prevalence of ASD nationally is 1%. About 1 in 110 US children have some form of ASD. (6) The increase in prevalence may be due to the change in diagnostic criteria, an increase in awareness of autism and an increase in the availability of funding and education services. (3, 7, 8) At present, the top 3 states with the highest prevalence of ASD are Arizona, Missouri and North Carolina (out of the 11 states in surveillance network). For the purpose of this study, it is noted that North Carolina has the third highest prevalence of ASD with an overall prevalence of 10.4 per 1000 8-year-old children. (6) In addition, North Carolina has the 4th greatest prevalence change (60%), from 6.5 per 1000 8-year-old children in 2002 to 10.4 per 1000 8-year-old children in 2006. (6)

Clinical needs

Children with development disabilities often present with complex medical and behavioral issues that could complicate oral health care. These include medications for their comorbid conditions, unique diets, sensory and motor impairments, language deficits, self-injurious behaviors, physical challenges, greater prevalence of aggressive and disruptive behaviors, anxiety and depression. (9) Rumination and tube feeding were found to be an important factor for the development of dental caries in children with severe motor and intellectual disabilities (10), while orofacial anomalies that accompanied some of the chromosomal disorders could further increase periodontal and caries risks. (9) (11) Children with intellectual disabilities were found to

have poorer oral health compared to healthy children. (11) The majority of oral health problems were periodontal-related, with high plaque and gingivitis scores. (12-14)

Although Altun et. al. (2010) found that children with ASD had better oral hygiene compared to those with other disabilities (15), many of their clinical features such as sensorimotor deficits (somatosensory, vision, auditory, vestibular function, muscle tone and joint laxity), impaired executive function, attention problems (overfocus or short attention span on certain activities), anxiety and depression, aggression and irritability, difficulties in comprehension and language disabilities(3) may hinder oral health care. These can make oral hygiene routines and behavior management of children with ASD difficult tasks for caregivers and dentists. Furthermore, medical condition such as mental retardation, seizure disorder, attention deficit hyperactivity disorder (ADHD), Fragile X syndrome, and gastro-intestinal problems may coexist in individuals with ASD. (3, 9, 16-18)

Successful management of these children in the dental environment involves preparation of parents and child outside the dental office, scheduling the child at appropriate times of the day, systematic desensitization to the environment, modification and flexibility in common techniques such as positive reinforcement, tell-show-do and negative reinforcement when necessary. (19, 20) Above all, having some knowledge and awareness of ASD and its associated features will facilitate the oral health care of this population.

Oral health needs

To date, few studies have explored the oral health status and dental needs of children with ASD. (20-25) Varies caries susceptibility and prevalence have been reported in different studies. Some revealed similar caries rates for children with ASD compared with a control group (20, 22, 24), while others showed a lower caries rate (22, 23). A recently published study reported that

autism may be considered an indicator for high caries risk, with oral hygiene being the most influential risk indicator associated with new caries in children with ASD. (25) In a population of 99 children with ASD, 59% with poor oral hygiene had new caries compared to 28% with good or excellent oral hygiene.(25) While this may not be surprising in any population, issues related to oral health care and access to qualified and experienced oral health professionals can create significant risk for these children receiving preventive care.

Unmet medical needs

The National Health Statement, Healthy People 2020, sets goals for improving access to health care services. (26) One of the proposed targeted areas is to reduce the proportion of individuals that experience difficulties or delays in obtaining necessary medical care, dental care, or prescription medicines. Access to care has been an ongoing problem, especially for children from low-income families, those enrolled in Medicaid, and children with special health care needs (CSHCN). (27-38) Among CSHCN, those with ASD were 2.14 more likely to have unmet needs and less access to important components of healthcare.(39) Long waiting time, cost of care, lack of health insurance, extent of outreach, parental awareness, family commitments, family stress levels, cultural and ethnic disparities, and parental education level were found to be associated with difficulties of accessing treatment services for children with ASD. (40-43) These findings reflect the impact of ASD on access to medical care.

Unmet dental needs

Of all the unmet health needs, the unmet dental need is the most prevalent.(44, 45) An estimate of 50% of children was reported to lack the recommended number of dental visits.(45) Although enrollment in other public health programs (other than Medicaid) has shown improvement in children's access and use of dental care, barriers to dental care remain apparent. (46, 47) The majority of studies that examined access to dental care in healthy children were

focused on Medicaid-eligible children or children from low-income families. The identified barriers include low family income, limited parental educational, poor oral health literacy and awareness about the importance of oral health, negative attitudes of dentist and office staff, ethnic and racial barriers, insurance status, willingness of dentists to treat, and distribution or location of dentists within some states and local communities. (27-29, 31-33, 48)

Although fewer studies have been done on CSHCN, these studies reported that dental care remained to be the most prevalent unmet healthcare need.(49, 50) It was reported that 78% of CSHCN needed dental care in the prior 12 months, while 10.4 % of CSHCN did not receive dental care when needed. (49) Factors associated with higher odds of unmet dental needs for CSHCN were found to be household income, severity of the associated medical condition, lack of insurance, and insurance lapses.(50) A recently published study targeted at a more involved subsample of CSHCN population and reported that 20% had unmet dental needs. Their findings suggest that the worse overall dental health and greater unmet needs may be due to their greater medical complexity.(51)

Three studies explored unmet dental needs among children with ASD. Data extracted from the 2003 National Survey of Children's Health (NSCH) did not show a statistical difference for dental care access measures between children with and without ASD. This study, however, did not explore barriers to dental care for children with ASD. (21) In a sample of 55 children with ASD, Brickhouse et al identified difficult behaviors in the dental office and household income as the major barriers to dental care. In addition, it was reported that 24% of these children did not have scheduled periodic dental care. (52) When the CSHCN population was subdivided, it was revealed that 23% of the autism group had unmet dental needs although it was not statistically significantly different compared to children with other medical conditions. (51)

SPECIFIC AIMS

The primary aim of this study was to survey a sample of caregivers with children with ASD to describe the barriers to dental care and unmet dental needs. The secondary aim was to examine the association of having unmet dental needs and 1) type of ASD and 2) child's perceived behavior in the dental office.

MATERIALS AND METHODS

Sample

The sample was obtained from the Autism Registry of North Carolina, which is part of the core services of the UNC Neurodevelopmental Disorders Research Center. It is a tool for research participant recruitment available to UNC researchers through the National Institute of Child Health and Human Development (NICHD)-funded Intellectual and Developmental Disabilities Research Center at the Carolina Institute for Developmental Disabilities (CIDD). Although the sample was obtained from a single state, North Carolina has a representative population of individuals with ASD due to its availability and diversity of autism-related services for children. (41) The registry database is primarily populated through a collaboration with Division TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children), which is a state-funded program that provides diagnostic and treatment services for individuals with Pervasive Developmental Disorders in nine centers across North Carolina. It currently has more than 4500 North Carolina residents diagnosed with ASD enrolled; 3441 are under 18 years old. One thousand and five hundred families with children with ASD were selected using a stratified random sampling scheme with weighted allocation.

Eligibility

The inclusion criteria include families with children age 18 and under who were diagnosed with ASD. If there were more than one child diagnosed with ASD in the family, the oldest child with ASD was considered as the subject of the questionnaire. The sole exclusion criteria was children who were above age 18. This study was approved by the Institutional Review Board of the University of North Carolina (Chapel Hill).

Measure

The survey framework was adapted from the Behavioral Model of Health Services Use. (53) The questionnaire included questions on basic demographics, predisposing factors, enabling factors, and need factors. Additional questions targeted to the ASD population inquired about the type and severity of ASD, the age of diagnosis, number of children diagnosed with ASD in the household, the association with autism-related organizations and the use of educational programs/services. For those who have been to a dentist, dental visit related questions were asked with regards to their child's last dental visit, the main problems faced during the last dental visit, the type of dental office and the frequency of the child's dental visits.

The initial questionnaire was pilot tested by caregivers with children with ASD who presented as patients in the UNC Graduate Pediatric Dentistry clinic. Feedback obtained led to modifications on the structure and wording of the questionnaire. The edited questionnaire and survey administration methods were further discussed and developed with experts from the UNC Odum Institute for the Research of Social Sciences.

To address the study's primary question (to determine the presence of unmet dental needs in children with ASD), the following question was asked:

- During the past 6 months was there a time when you wanted to get dental care for your child but could not get it at that time?

For caregivers who answered "no" to the above question, follow-up descriptive questions that addressed the main barriers to dental care were asked. Multiple answers were allowed for this descriptive section.

The questionnaire was translated into Spanish. Copies of the English and Spanish questionnaires are included in the Appendix.

Data collection

The survey was conducted from March to May 2010. All mailings were handled by two staff members from the Autism Registry in UNC Neurodevelopmental Disorders Research Center. The investigators did not have access to the mailing list due to confidentiality issues and all questionnaires were anonymous. An identification number was assigned to each questionnaire for the purpose of tracking of non-respondents only. A total of three separate mailings were sent. (54) The first mailing, consisting of an information sheet, the questionnaire and a return envelope, was sent to all selected participants. Two weeks later, a reminder card was sent to all non-respondents. A final mailing, consisting of the questionnaire, information sheet and return envelope, was sent to all non-respondents four weeks after the initial mailing. For Hispanic families, both the English and Spanish questionnaires were mailed. Collection of questionnaires ended at six weeks after the initial mailing. All received questionnaires were scanned by an automatic reader.

DATA ANALYSIS

The definition of “having unmet dental needs” was the inability to get dental care when needed in the past six months. The major independent variables were the type of ASD and child’s behavior in the dental office. The dependent variable was “having unmet dental needs”.

The survey data was managed using Statistical Analysis Systems (SAS®) Version 9.1.3. Descriptive analyses that were calculated include frequencies and percentages for categorical variables, and means and standard deviations for continuous variables. The Fisher’s exact test was used for bivariate analyses to examine the relationships between the dependent and independent variables. The statistical significance was set at 0.05 level.

A multivariate regression model was used to examine the relationships between the dependent and independent variables after controlling for potential confounding covariates. The number of independent variables included in the regression model was limited by the sample size. Highly-correlated explanatory variables in the same regression model could create problems in estimation. The variance inflation factor (VIF), a measure of multicollinearity, was used to assess the correlation of the two explanatory variables. Running a regression with the two explanatory variables yielded VIF values of 1.0 for both variables, which was well below the lowest recommended value of concern, a VIF of 2.5.

Odds ratios (ORs) and 95% confidence intervals (CIs) were used to present the logistic regression analyses. The statistical significance was set at 0.05 level. The final model for the outcome were derived by “child’s behavior in dental office” and “type of ASD” as the primary explanatory variables, and employing forward selection to determine if any other explanatory or

covariate variables were significantly related to the outcome. Four explanatory variables were included in the final model: “child’s behavior in dental office”, “type of ASD”, “child’s dental health status”, and “time since caregiver’s last dental visit”.

Child’s behavior and child’s dental health status mentioned in this study refers to behavior and dental health as perceived by their caregivers respectively.

RESULTS

The response rate was 37% (N=568). Six questionnaires were rejected due to scanning errors. Two subjects did not meet the inclusion criteria, while five were excluded because the caregivers did not answer the question that was related to the dependent variable. A total of 555 questionnaires were complete and used in data analysis. Not all respondents answered every question. The missing values were excluded in the denominator for the calculation of percentages.

Descriptive results

The demographic characteristics of children with ASD and caregiver factors are summarized in Tables 1. The majority of children were males, white and non-Hispanic. The mean age was 9.9 years old, with a standard deviation (SD) of 3.9 years. Only 3.5% of the children were not attending school. Slightly more than half of the children had private dental insurance only and approximately 75% had an average household income of \$35,000 or greater. The majority of the caregivers were at least high school graduates, with 56.6% being college graduates. Seventy-five percent of the caregivers reported the last dental visit within the past year.

Information on the autism-related factors and the child's medical condition are summarized in Table 2. Approximately 40% of the children were diagnosed with autistic disorder and Asperger's disorder respectively. The distribution of autism severity in each type of ASD was presented in Table 3. There were more children with severe ASD in autistic disorder type, while more children were of milder ASD in Asperger's disorder and PDD-NOS types. The mean age of diagnosis was 5.2 years old (SD=3.1). Approximately 40% of the children had some co-existing medical condition, with the majority being psychiatric and behavioral conditions. Attention deficit hyperactivity disorder (ADHD) was the most commonly co-existing medical condition. The

majority of the children received medical care by family physicians, with 95% of them having regular care.

As summarized in Table 4, the child's behavior in the dental office was evenly distributed, with approximately 25% in each behavior category - poor, fair, good, and excellent. Close to 80% of the caregivers reported that their child's dental health was in good or excellent condition. Child's dental health status mentioned in this study refers to dental health as perceived by their caregivers.

The proportion of children with unmet dental needs and dental visit characteristics was summarized in Table 5. Overall, only 11.7% of the caregivers reported an unmet dental need in the past 6 months. Although the majority of the children (94.2%) had been to a dentist, 11% of these children still reported unmet needs. Among the children who had been to a dentist, about 90% of them had their last dental visit within the past year and 75% visited their dentists every 3 to 6 months. The two most common problems at the child's last dental visit were reported to be the child's behavior (29.8%) and the clinic not accepting Medicaid (21.0%).

Descriptive data on barriers to dental care is summarized in Table 6. For those who had an unmet dental need in the past 6 months, the most commonly reported barriers were the child's cooperation (60.0%), cost of care (38.5%) and lack of dental insurance (23.1%).

Analytical results

When the relationship of the covariates and the outcome variable were assessed with bivariate analyses, the following variables were significantly associated with having unmet dental care needs (Tables 7 and 8): (1) average household income ($p=0.02$); (2) dental insurance coverage ($p=0.04$); (3) caregiver's education level ($p<0.001$); (4) child's behavior in dental office

($p < 0.001$); (5) child's dental health status ($p < 0.001$); (6) caregiver's last dental visit ($p < 0.001$) and (7) the type of dental office ($p = 0.002$).

Table 9 shows factors related to having unmet dental needs after multivariate analysis. Children with "good" and "excellent" behavior in dental office were collapsed into one group for the analysis.

Having unmet dental needs was associated with the time since caregiver's last dental visit, specifically more than 6 months to 1 year ($OR = 2.58$, 95% $CI = 1.07-6.26$, $P < .001$), and more than 1 year to 3 years ($OR = 3.26$, 95% $CI = 1.65-6.47$, $P < .001$).

Improving behavior in the dental office had a protective effect on having unmet dental needs. Children with fair and good behavior had decreased odds of having unmet dental needs ($OR = 0.41$, 95% $CI = 0.19-0.86$, $P = 0.01$; $OR = 0.37$, 95% $CI = 0.17-0.80$, $P = 0.01$) compared to those with poor behavior in the dental office.

Having good dental health status also had a protective effect. Children who were perceived to have good dental health had decreased odds of having unmet dental needs compared to those with poor perceived dental health status ($OR = 0.17$, 95% $CI = 0.07-0.39$, $P < 0.001$).

Children with a diagnosis of either Asperger's syndrome or PDD-NOS was not significantly associated with having unmet dental needs compared to those with autistic disorder ($P = 0.89$).

DISCUSSION

Prevalence of unmet dental needs

Dental care remains the most prevalent unmet healthcare needs for children with and without special needs.(34, 48) This study reported 12% of children with ASD had unmet dental needs in the past 6 months. The prevalence was higher compared to previous studies. (34, 49). Data extracted from a 4-year National Health Interview Survey (NHIS) (1993-1996) revealed that 5.3% of children had unmet dental needs in the past year (44), while 10.4% of CSHCN reported unmet needs in a separate survey.(49) Our study was the second study that focused on unmet dental needs in children with ASD. Brickhouse reported 19% of children with ASD having unmet dental needs in the past 12 months, which was higher than the current study. The difference could be due to sampling from a different population and having a larger sample size in our study. Nelson et al subdivided their sample of CSHCNs and reported that 23% of children with autism had unmet dental needs.(51) However, this was not found to be statistically significantly different from CSHCNs with other conditions. The higher prevalence of unmet dental needs in their study could be due to a more involved specifically targeted population of CSHCNs, who presented with greater medical complexity.

Barriers to dental care

Our findings revealed that although the majority of children with ASD (94%) had been to a dentist, 11% still reported unmet dental needs. This suggests that unmet dental needs still exist although children with ASD seemed to have good access to dental care, as indicated by the reported dental visits. The main cited barriers to dental care were the child's behavior, cost of dental care and lack of dental insurance. These were consistent with other national studies

reporting on the general child population and CSHCN. Limitations attributed to disability and difficult behaviors hindered children from getting dental care when needed in addition to the commonly reported barriers. (49, 52) In this study, the child's behavior was the major barrier to dental care and the most frequently cited problem during the child's last dental visit. The child's behavior in the dental office was also found to be associated with having unmet dental needs in the bivariate and multivariate analyses. Children with poor perceived behavior in the dental office had higher odds of having unmet dental needs after controlling for effects from covariates. Our findings were not surprising in that children with ASD possessed many behavioral clinical features such as sensorimotor deficits, impaired executive function, attention problems, aggression, irritability, difficulties in comprehension and language disabilities, that could complicate oral health care at home and in the dental office.

Although a previous study (52) had reported on unmet dental needs among children with ASD, our study was the first to examine the relationship between unmet dental needs and the type of ASD. Children with different types of ASD present with unique clinical features and the severity of the condition within each type of ASD also differs among individuals. In contrast to our hypothesis that a different degree of dental needs may exist among children with different types of ASD, our findings did not detect any differences in having unmet dental needs. The effect of ASD on unmet dental needs may be diluted by the variability of severity within each type of ASD. The degree of severity in one type of ASD does not correlate with another type. For example, a child with mild autistic disorder differs in behavior compared to a child with mild Asperger's syndrome.

The finding that children with good perceived dental health had lower odds of having unmet dental need was not surprising because children with better dental health would be less likely to have dental needs. However, it must be noted that the dental health status was self-

reported by caregivers, and the definitions of poor, fair and good dental health were not specified in the questionnaire. A clinical dental examination was not performed to verify caregiver's opinion of the child's dental health status. Caregiver's perception on the child's dental health may differ from the actual dental health, and could be affected by their knowledge, attitude, awareness of oral health, and previous dental experience. In addition, time since caregiver's last dental visit was found to have an effect on having unmet dental needs. Children whose caregivers had their last dental visits more than six months ago had higher odds of having unmet dental needs. This relationship reinforced the earlier assumption that caregiver's attitude may have affected the likelihood of getting dental needs met for children with ASD. Caregivers who had their dental visit less than six months ago may be more conscientious in maintaining good dental health, and are more likely to bring their children for timely and regular dental visits, therefore less unmet dental needs.

Significance and future directions

The child's behavior was found to be the major barrier to care in this study and previous studies.(50, 52) Our study reinforces the importance of behavior management of children with ASD in the dental office. Future research should be focused on the following areas: child, caregiver, dental and medical health care providers.

Child

Studies investigating behavior management or modification interventions for children with different type of ASD before and during dental visit may provide insights into helping these children cope with dental procedures. Children with autism may be acclimatized to the dental environment after a certain number of dental visits or caregivers may decide to decrease the frequency of dental visits due to the children's poor behavior in previous dental visits. Prospective clinical studies examining changes in cooperation with dental procedures in children with autism

over a certain time period may provide an insight on the effect of behavior management intervention and recommendations for dental visits. This may serve as a basis for professional recommendations and for parental counseling. In addition, the influence of child's age on behavior may be different among children with and without ASD. Behavior management of younger children with ASD may be relatively easier (employing physical active restraint if child's behavior is challenging in the dental office), compared to older children with ASD (when physical restraint may be difficult, and alternative pharmacological behavior management methods have to be considered). A prospective or cross-sectional clinical study may be done to examine the relationship between child's age and behavior management strategies.

Caregiver

Caregiver's perception of behavior may under-estimate or over-estimate child's actual behavior, especially for those who have never been to the dentist. In addition, child may respond differently to different dental procedures. Future studies may examine the association between the caregiver's perception of child's behavior in the dental office with the actual behavior of the child as assessed by the clinicians.

Dental health care providers

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

Training in caring for special needs patients seems to be inadequate. A survey of dental school programs revealed that only 64% offered a separate course about special needs patients. (55) Wolff et al reported 50.8% of dental students surveyed had no clinical experience in caring for patient with mental retardation and 60% reported having little or no confidence in providing

care.(56) In a recently published study regarding pediatric and general dentists' professional attitudes towards patient with ASD, a majority of the respondents indicated that they received inadequate training in their predoctoral dental education in treating patient with ASD. The study also found that the quality of pediatric dentists' education experiences correlated with the frequency of appropriate behavior management strategy used when treating patients with ASD.(57)

Pilot training programs for caring of patients with special needs 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 for updates on current evidence and behavior management of children with special needs in dental settings.

Medical health care providers

The majority of the children (95%) in this study had regular medical care by their family physicians, while 75% had regular dental visit at least every six months. Although this study did not investigate unmet medical needs among children with ASD, the findings seemed to suggest that this sample of children with ASD had more encounters with physicians than dental professionals. An interdisciplinary team approach with the child's physician may help to overcome or manage the behavior of the child with ASD, which was reported to be the major barrier to dental care and most frequently cited problem at the child's last dental visit. An oral health assessment may be incorporated in a physician's visit and an appropriate referral base or connection may be established. Pilot programs involving individualized interventions with a team approach may be designed for each child to help them cope with dental procedures, and improve oral health care in these children.

Future cross-sectional surveys should sample children across the nation, and to be administered to families with children with and without ASD, so that results could be generalized to the general population. The questionnaires may also be linked to clinical oral examinations of the children so that the actual dental health status can be determined by professionals.

Study limitations

We acknowledge several limitations when conducting this research study. One of the limitations of this study is the response rate. The average reported mail-in response rate of the Autism Registry of North Carolina was 30%. Although we tried to increase the response rate through three separate mailings, the current study had a response rate of 38%. The relatively low response rate could be due to the length of the questionnaire.

We attempt to analyze the difference between respondents and non-respondents using characteristics provided from the Autism Registry of North Carolina. (Table 10) Families who were from Raleigh and east of Raleigh were categorized as “east”, those from west of Raleigh were categorized as “west”. Although the bivariate analyses using chi-square tests revealed that respondents and non-respondents were statistically significantly different with regards to the child’s race ($P=0.004$), the association between child’s race and having unmet dental needs (the outcome variable) was not statistically significant ($P=0.85$) as reported in the result section. Child’s gender ($P=0.52$) and location ($P=0.63$) in North Carolina were not significantly different among respondents and non-respondents. Therefore, with the limited information available for comparison between respondents and non-respondents, we believe that the respondent population is representative of the 1500 families who were randomly selected for this study.

Selection bias is the major limitation in this study. Families who have registered with the autism registry may have better access and utilization to health care resources. Because the questionnaires were mailed through the autism registry, institutionalized children and those who were not registered with the registry were omitted in the study. In addition, those who are illiterate or do not understand English or Spanish would not be able to complete the survey. These individuals may be the ones who truly have difficulties in accessing health care and have unmet needs. As such, outcome of this study may not be generalized to the whole population of individuals with ASD. The overall prevalence of unmet dental needs in children with ASD may be underestimated.

There could also be an under-estimation or over-estimation of the unmet need prevalence as a result of having a different time period of six months, compared to those in previous studies where they looked at unmet needs in the past twelve months. An underestimation could occur because children with unmet dental needs beyond six months were not included in the study. More children could have unmet needs between the past six to twelve months. On the other hand, there might be an overestimation of unmet needs because some children could have seen the dentist in the past six to twelve months. Fewer children would have unmet dental needs in this circumstance. The recommended frequency of dental visit for children and adolescents was twice yearly (every six months) based on individual's risk status. (2) Children with special health care needs were considered high-risk individuals who required dental visits at least every six months. Therefore, a six-month period was chosen for this questionnaire.

As with other self-reported cross-sectional studies, we acknowledge the reporting bias with regards to the reliance on caregivers' reports. The caregiver's assessment of behavior may or may not represent the actual behavior of the child, especially when each child differs in behavior under different situations and interaction with other individuals. In addition, the caregiver's

assessment may not be accurate for those children who had not been to the dentist. We also did not specify the dental procedures performed. There would likely be a difference in response to dental treatment, depending on the type of dental procedures performed. Without clinical oral examinations and assessments in the dental office, caregivers' reports may not accurately reflect the true dental needs, dental health status and behavior of the child in dental office. In addition, there are many different dental needs relating to oral hygiene, caries, trauma or orthodontics. We did not identify the type of dental needs that were needed in this study.

Although this study was designed to focus on children with ASD and included questions that examined factors that may have possible effect of autism on having unmet dental needs, it was generally a descriptive study and did not have utilize a control group for comparison.

CONCLUSION

Although the majority of children with ASD had been to a dentist, 12% reported unmet dental needs in the past six months. The major barrier to dental care appeared to be child's behavior. The type of ASD was not associated with unmet dental needs. Strategies to further minimize unmet dental needs should focus on increasing patient cooperation in the dental office and consider an interdisciplinary team approach with the child's physician.

TABLES

Table 1. Demographic characteristics for children with ASD (N=555)

	N	%		N	%
Sex			Type of dental insurance		
Male	464	83.6	Private only	301	54.4
Female	91	16.4	Medicaid only	159	28.8
			Medicaid and Private	18	3.3
Race			None	75	13.6
Black	43	7.8	Missing	2	-
White	466	84.9			
Other	40	7.3	Type of community		
Missing	6	-	Rural	182	33.6
			Suburban	274	50.7
Ethnicity			Urban/City	85	15.7
Hispanic or Latino	22	4.0	Missing	14	-
Not Hispanic or Latino	529	96.0			
Missing	4		Last dental visit for caregiver		
			≤6 months	367	66.1
Average household income			6 months – 1 year	51	9.2
<\$35,000	144	26.6	>1 – 3 years	81	14.6
\$35,000-74,999	199	36.7	> 3 years/never been/do not know or remember	56	10.1
≥\$75,000	199	36.7			
Missing	13	-	School attendance		
			Yes	529	96.5
Caregiver's education			No	19	3.5
Did not complete HS	18	3.3	Missing	7	-
HS graduate	221	40.1			
College graduate	312	56.6	Age of child (years)	Mean (SD)	Median (Range)
Missing	4	-	Missing=2	9.9(3.9)	10.0(2.0-18.0)

Table 2. Autism-related factors and medical condition (N=555)

	N	%
Type of ASD		
Autism Disorder	216	38.9
Asperger's syndrome	210	37.8
PDD-NOS	129	23.3
No. of children in household with ASD		
1	513	92.4
More than 1	42	7.6
Other Medical Conditions		
Yes	230	41.5
No	324	58.5
Missing	1	
Type of Medical Conditions*		
ADHD	89	39.0
Behavioral/ psychiatric conditions	47	20.6
Cerebral palsy/seizure disorders	15	6.6
Other	77	33.8
Medical care by family physicians		
Yes	535	97.0
No	16	3.0
Missing	4	
Reasons for seeing family physicians		
Regular check-ups only	82	15.6
Illness only	27	5.2
Both	416	79.2
Missing	30	
Child registered with organization[†]		
Autism Society of NC	333	60.0
TEACCH	495	89.2
CDL	18	3.2
Age of diagnosis		
Mean (SD)	Median (Range)	
Missing=4	5.2(3.1)	4.4(1.0-16.0)

* Only those who answered "yes" to the question "Does your child have any other medical conditions?" responded.

† Multiple answers were allowed for the question.

Table 3. Distribution of autism severity in each type of ASD (N=555)

	N	%
Autism Disorder		
Mild	91	46.7
Moderate	77	39.5
Severe	27	13.8
Asperger's syndrome		
Mild	129	66.8
Moderate	58	30.1
Severe	6	3.1
PDD-NOS		
Mild	73	62.9
Moderate	37	31.9
Severe	6	5.2

Table 4. Caregiver's perception of child's cooperation and dental health (N=555)

	N	%
Child's perceived cooperation in dental office		
Poor	150	27.1
Fair	137	24.7
Good	142	25.6
Excellent	125	22.6
Missing	1	
Child's perceived dental health status		
Poor	21	3.8
Fair	83	15.0
Good-Excellent	450	81.2
Missing	1	

Table 5. Unmet dental needs and dental visit characteristics (N=555)

	N	%
Child needed dental care but did not get it in the past 6 months		
Yes	65	11.7
No	490	88.3
Child ever been to a dentist		
Yes	523	94.2
No	32	5.8
Child's frequency of dental visit*		
Every 3 to 6 months	391	75.2
Once a year	72	13.8
Only when pain occurs/other	57	11.0
Missing	35	
Child's last dental visit*		
≤6 months	390	74.6
6 months to 1 year	56	10.7
1 year to 3 years	54	10.3
> 3 years/do not know or remember	23	4.4
Missing	32	
Type of dental office*		
General practice	195	37.6
Pediatric Dentistry	298	57.5
Other	25	4.8
Missing	37	
Main problems at last dental visit*[†]		
Dentist/assistant was not able to handle my child	50	9.6
Dentist/assistant did not treat me or my child with respect	22	4.2
Dentist did not treat young children	5	1.0
Dentist did not treat special needs children	43	8.2
My child could not cooperate	156	29.8
Clinic did not accept Medicaid	11	2.1
Clinic was not "special-needs" friendly	39	7.5
Child's anxiety	19	3.6
None	180	34.4

* Only those who answered "yes" to the question "Have your child been to a dentist?" responded.

[†] Percentage calculated out of those who had been to a dentist (N=523); multiple answers were allowed for the question.

Table 6. Caregiver-reported barriers to dental care (N=65)

	Main reasons why child could not get care when he/she needed dental care during the past 6 months*	
	N	%
Could not afford it	25	38.5
No insurance	15	23.1
Dentist did not accept Medicaid/insurance	6	9.2
No dentist available	11	16.9
Transportation problem	6	9.2
Health of another family member	5	7.7
Other things in the family to be taken care of	7	10.8
Hours not convenient due to work	8	12.3
Wait too long in clinic/office	9	13.8
Difficulty in getting appointment	12	18.5
Did not know where to go	7	10.8
Didn't like/trust/believe in dentists	5	7.7
Patient's medical condition	1	3.1
Language barrier	1	1.5
Child was uncooperative	39	60.0
Child was too young	3	4.6
Baby teeth will "fall out" by themselves soon	-	-
Child's oral condition was very good and did not need to see a dentist	-	-
Child's dental condition was not serious enough to see a dentist	-	-

* Multiple answers were allowed for the question.

Table 7. Bivariate correlation of independent variables and outcome variables (N=555)

	Child needed dental care but did not get it in the past six months N(%)		P-value
	Yes	No	
Diagnosis of Child			0.72
Autism Disorder	28(43.1)	188(38.4)	
Asperger's Syndrome	22(33.9)	188(38.4)	
PDD-NOS	15(23.0)	114(23.2)	
No. of children diagnosed with ASD			0.21
1	63(96.9)	450(91.8)	
More than 1	2(3.1)	40(8.2)	
Presence of other medical conditions			0.42
Yes	30(46.1)	200(40.9)	
No	35(53.9)	289(59.1)	
Type of community			0.07
Rural	28(44.4)	154(32.2)	
Suburban	30(47.6)	244(51.1)	
Urban/City	5(8.0)	80(16.7)	
Ethnicity			0.50
Hispanic	1(1.5)	21(4.3)	
Non-Hispanic	64(98.5)	465(95.7)	
Race			0.85
Black	6(9.2)	37(7.6)	
White	55(84.6)	411(84.9)	
Others	4(6.2)	36(7.4)	
Average household income			0.02*
<\$35,000	26(40.0)	118(24.7)	
\$35,000-\$74,999	23(35.4)	176(36.9)	
≥\$75,000	16(24.6)	183(38.4)	
School attendance			0.26
Yes	59(93.7)	470(96.9)	
No	4(6.3)	15(3.1)	
Dental insurance coverage			0.04*
Private only	25(39.0)	276(56.4)	
Medicaid only	24(37.5)	135(27.6)	
None	11(17.2)	64(13.1)	
Medicaid and private	4(6.3)	14(2.9)	
Age (mean(SE); years)[‡]	8.3(0.5)	9.6(0.2)	0.18
Age of diagnosis (mean(SE); years)[‡]	4.0(0.4)	5.0(0.1)	0.31

*Statistically significant level at 0.05.

[†] "Not sure" category was not included in bivariate analysis.

[‡] T-test used for continuous variables.

Table 8. Bivariate correlation of independent variables and outcome variables (N=555)

	Child needed dental care but did not get it in the past six months N(%)		<i>P</i>
	Yes	No	
Caregiver's education level			<.001*
Did not complete high school	1(1.6)	17(3.5)	
High school graduate	43(67.2)	178(36.6)	
College graduate	20(31.3)	292(59.9)	
Caregiver's perception of child's behavior in dental office			<.001*
Poor	35(53.9)	115(23.5)	
Fair	14(21.5)	123(25.2)	
Good	8(12.3)	134(27.4)	
Excellent	8(12.3)	117(23.9)	
Caregiver's perception of child's status of dental health			<.001*
Poor	5(7.6)	16(3.2)	
Fair	25(38.5)	58(11.9)	
Good-Excellent	35(53.9)	415(84.9)	
Missing=1			
Last dental visit for caregiver			<.001*
≤6 months	26(40.0)	341(69.6)	
6 months – 1 year	10(15.3)	41(8.4)	
1 – 3 years	22(33.9)	59(12.0)	
> 3 years	7(10.8)	49(10.0)	
Type of dental office			0.002*
General practice	19(33.9)	176(38.1)	
Pediatric dentistry	28(50.0)	270(58.4)	
Others	9(16.1)	16(3.5)	

*Statistically significant level at 0.05.

Table 9. Factors associated with the odds of having unmet dental need in children with ASD. (N=555)

	OR	95.0% C.I.	P-value
Perceived behavior in dental office			0.01*
Poor	reference	-	
Fair	0.41	0.19-0.86*	
Good	0.37	0.17-0.80*	
Type of ASD			
Autistic disorder	reference	-	0.89
Asperger's syndrome	1.16	0.58-2.31	
PDD-NOS	1.17	0.54-2.51	
Caregiver's last dental visit			<0.001*
≤ 6 months	reference	-	
> 6 months to 1 year	2.58	1.07-6.26*	
> 1 year to 3 years	3.26	1.65-6.47*	
> 3years/ do not remember	0.79	0.28-2.27	
Dental health status of child			0.002*
Poor	reference	-	
Fair	0.66	0.33-1.30	
Good	0.17	0.07-0.39*	

Parameters are odd ratio (OR) and 95% confidence interval (CI).

*Statistically significant level at 0.05.

Table 10. Bivariate correlation of variables between respondents and non-respondents (N=1500)

	Respondent N(%)	Non-respondent N(%)	P
Child's gender			0.52
Male	488(83.7)	778(84.9)	
Female	95(16.3)	138(15.1)	
Missing=1			
Child's race			0.004*
White	463(82.4)	664(76.1)	
Non-white	99(17.6)	209(23.9)	
Missing=65			
Location in North Carolina			0.63
East	266(45.6)	430(46.9)	
West	317(54.4)	487(53.1)	

*Statistically significant level at 0.05.

Appendix A: Sample Questionnaire (English)

UNC DEPARTMENT OF PEDIATRIC DENTISTRY Access to Dental Care for Children with Autistic Spectrum Disorder

2010

ID:

INSTRUCTIONS: Please use pen to complete forms. Fill in circles completely for the most appropriate option or fill in the blanks as needed. Please fill in only ONE option for each question unless otherwise specified.

The survey should be filled out by the primary caregiver. The primary caregiver is defined as the adult responsible for coordinating the dental care of the child, as based on self-report, defined as a parent, grandparent, aunt, uncle, or guardian. When multiple individuals are responsible for the child, the individual who considers himself or herself the child's primary caregiver for oral health-related matters will be used. All subsequent reference to caregiver will follow this definition.

1. What is your relationship to the child? (Please choose ALL that apply)

☐ Parent ☐ Legal Guardian ☐ Grandparent ☐ Other (please specify): _____

2. How many children under 18 years old live in your household? If none, record zero.

3. Are there any children in your household who are diagnosed with Autism Spectrum Disorder?

☐ Yes ☐ No (Thank you for looking at the survey. This survey is only for households with autistic children. Please return the papers in the return envelope.)

4. How many of your children have a diagnosis of Autism Spectrum Disorder (ASD)? Write the number in the box

5. Which of the following diagnoses has been made for your child? (If you have more than one child with ASD, answer for the oldest one.)

☐ Autism Disorder (Classic Autism) ☐ Asperger's syndrome
☐ Pervasive Developmental Disorder - Not otherwise specified (PDD-NOS)

6. If you have more than one child with ASD, what is the diagnosis of the next oldest child?

☐ Only one child affected - Not applicable ☐ Autism Disorder ☐ Asperger's syndrome ☐ PDD-NOS

The rest of the questions relate to the oldest child with ASD - the child in question 5.

7. What is the current severity of the ASD?

☐ Mild ☐ Moderate ☐ Severe ☐ Not sure

8. What is the age of your child?

years of age (round to the nearest year)

9. At what age was the ASD diagnosis made?

years of age (round to the nearest year)

10. Does your child have any other medical condition?

☐ No
☐ Yes (Please specify) _____

11. Is your child currently taking any prescribed medications?

- ☐ No
☐ Yes (Please name the medication(s) and state what condition(s) they are for)

12. Has your child taken any (other) prescribed medication in the past?

- ☐ No
☐ Yes (Please name the medication(s) and state what condition(s) they are for)

13. Does your child see a family physician for medical care? ☐ Yes ☐ No (Please skip to Question 15)

14. Why does your child see a family physician? ☐ Regular checkups ☐ Illness only ☐ Both

15. Is your child registered with any of the following organizations? (Please choose ALL that apply)

- ☐ Autism Society of North Carolina ☐ TEACCH
☐ Clinical Center for the Study of Development and Learning
☐ Other organizations related to child's ASD condition (Please specify)

16. Does your child attend school (including preschool)? ☐ Yes ☐ No (Please skip to Question 18)

17. What educational services does your child receive in school? (Please choose ALL that apply)

- ☐ None ☐ Individualised Educational Program ☐ Inclusion ☐ Special
☐ Community Alternative Program (CAP) ☐ Other (Please specify)

18. What is your child's educational level?

- ☐ Too young for school ☐ Pre-school or Kindergarten ☐ 1st to 3rd grade ☐ 4th to 6th grade
☐ 7th to 9th grade ☐ 10th to 12th grade ☐ Withdrawn from school

19. Where does your child live? ☐ At home ☐ Institution ☐ Group Home ☐ Caregiver's place

20. What type of community does your family live in? ☐ Rural ☐ Suburban ☐ Urban / City

21. Describe your household:

- ☐ 2-parent ☐ Single parent ☐ Extended family ☐ Other (Please specify)

22. What is your annual average household income?

- ☐ Less than \$35,000 ☐ \$35,000 - \$49,999 ☐ \$50,000 - \$74,999 ☐ \$75,000 or above

23. What type of dental insurance does your child have?

- ☐ Private insurance - such as through an employer or an individual/family policy you purchased on your own
☐ Public insurance(Medicaid/Health Choice) ☐ No dental insurance

24. What type of medical insurance does your child have?

- ☐ Private insurance - such as through an employer or an individual/family policy you purchased on your own
☐ Public insurance(Medicaid/Health Choice) ☐ No medical insurance

25. What is your educational level?

- ☐ Didn't complete High School ☐ High School Graduate or Graduate-Equivalent Diploma
☐ 2 year degree or some College (including Community College, Technical School)
☐ Completed College ☐ Other (Please specify) _____

26. About how long has it been since you last visited a dentist?

- ☐ 6 months or less ☐ More than 6 months, but not more than 1 year ago
☐ More than 1 year, but not more than 3 years ago ☐ More than 3 years ago
☐ Never been to a dentist ☐ Don't know / Don't remember

27. Are there difficulties in carrying out oral hygiene procedures for the child?

- ☐ Yes ☐ No

28. On a scale from 1 to 10, how cooperative do you think your child is with dental procedures?

- Totally uncooperative 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ Very cooperative

29. Do you think dental health is important?

- ☐ Yes ☐ No

30. In your opinion, what is the status of your child's dental health?

- ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ Has no natural teeth

31. During the past 6 months, did your child have a toothache?

- ☐ Yes ☐ No ☐ Don't know / don't remember

32. During the past 6 months, was there a time when your child needed dental care but could not get it at that time?

- ☐ Yes ☐ No (PLEASE SKIP TO QUESTION 34) ☐ Don't know / Don't remember (PLEASE SKIP TO QUESTION 34)

33. The last time that your child could not get the dental care he/she needed, what were the main reasons he/she could not get care? (Please choose ALL that apply)

- | | |
|--|--|
| <input type="radio"/> Could not afford it | <input type="radio"/> No insurance |
| <input type="radio"/> Dentist does not accept Medicaid/insurance | <input type="radio"/> No dentist available |
| <input type="radio"/> No way to get there (transportation problems) | <input type="radio"/> Health of another family member |
| <input type="radio"/> There are other things in the family to be taken care of | <input type="radio"/> Hours not convenient due to work |
| <input type="radio"/> Wait too long in clinic / office | <input type="radio"/> Difficulty in getting appointment |
| <input type="radio"/> Didn't know where to go | <input type="radio"/> Don't like / trust / believe in dentists |
| <input type="radio"/> Patient's medical condition | <input type="radio"/> Speak a different language |
| <input type="radio"/> My child is uncooperative | <input type="radio"/> My child is too young |
| <input type="radio"/> Other reason (Please specify) _____ | |

34. Has your child ever been to the dentist? ☐ No ☐ Yes (PLEASE SKIP TO QUESTION 36)

35. If your child has never received dental care, what are the main reasons your child has never received dental care?
(Please choose ALL that apply)

- | | |
|--|---|
| <input type="radio"/> Could not afford it | <input type="radio"/> No insurance |
| <input type="radio"/> Dentist does not accept Medicaid/insurance | <input type="radio"/> No dentist available |
| <input type="radio"/> No way to get there (transportation problems) | <input type="radio"/> Health of another family member |
| <input type="radio"/> There are other things in the family to be taken care of | <input type="radio"/> Hours not convenient due to work |
| <input type="radio"/> Wait too long in clinic / office | <input type="radio"/> Difficulty in getting appointment |
| <input type="radio"/> Didn't know where to go | <input type="radio"/> Baby teeth will "fall out" by themselves soon |
| <input type="radio"/> Don't like / trust / believe in dentists | <input type="radio"/> Child's medical condition |
| <input type="radio"/> Speak a different language | <input type="radio"/> My child is likely to be uncooperative |
| <input type="radio"/> My child is too young | |
| <input type="radio"/> My child's oral health is very good and does not need to see a dentist | |
| <input type="radio"/> My child's dental condition is not serious enough to see a dentist | |
| <input type="radio"/> Other reason (Please specify) _____ | |

PLEASE SKIP TO QUESTION 41

36. About how long has it been since your child last visited a dentist?

- | | |
|---|--|
| <input type="radio"/> 6 months or less | <input type="radio"/> More than 6 months, but not more than 1 year ago |
| <input type="radio"/> More than 1 year, but not more than 3 years ago | <input type="radio"/> More than 3 years ago |
| <input type="radio"/> Don't know / Don't remember | |

37. Why did your child go to the dentist for the most recent visit?

- | | |
|--|---|
| <input type="radio"/> Check-up, examination or cleaning | <input type="radio"/> Something was wrong, bothering or hurting |
| <input type="radio"/> Went for treatment of a condition that dentist discovered at earlier check-up or examination | |
| <input type="radio"/> Don't know / don't remember | <input type="radio"/> Other (Please specify) _____ |

38. What were the main problems faced during your child's most recent dental visit? (Please choose ALL that apply)

- | | |
|--|--|
| <input type="radio"/> Dentist and/or assistant was not able to handle my child | <input type="radio"/> Dentist and/or assistant did not treat me or my child with respect |
| <input type="radio"/> Dentist does not regularly treat young children | <input type="radio"/> Dentist does not regularly treat special needs children |
| <input type="radio"/> My child could not cooperate | <input type="radio"/> Dentist does not accept Medicaid |
| <input type="radio"/> Clinic was not "special-needs" friendly | |
| <input type="radio"/> Other (Please specify) _____ | |

39. How often does your child visit the dentist?

- | | | | |
|--|--------------------------------------|-----------------------------------|---|
| <input type="radio"/> Every 3 months | <input type="radio"/> Every 6 months | <input type="radio"/> Once a year | <input type="radio"/> Only when pain occurs |
| <input type="radio"/> Other (Please specify) _____ | | | |

40. What type of dental office does your child go to for dental care?

- | | | | |
|--|---|--|---|
| <input type="radio"/> General Practice | <input type="radio"/> Pediatric Dentistry | <input type="radio"/> Hospital Dental Clinic | <input type="radio"/> Health Department |
| <input type="radio"/> Other (Please specify) _____ | | | |

41. What is your child's gender? ☐ Male ☐ Female

42. What is your child's ethnicity? ☐ Hispanic or Latino ☐ Not Hispanic or Latino

43. What is your child's race?

☐ American Indian / Alaska Native

☐ Asian

☐ Native Hawaiian / Other Pacific Islander

☐ Black / African American

☐ White / Caucasian

☐ Multi-racial

☐ Other (Please specify) _____

Thank you for participating in this survey.

*Your opinion is much valued and appreciated in improving dental care access for children.
Please mail this survey back in the envelope provided.*

Thank You!

Appendix B: Sample questionnaire (Spanish)

2010

UNC DEPARTMENT OF PEDIATRIC DENTISTRY
Access to Dental Care for Children with Autistic Spectrum Disorder

ID:

INSTRUCCIONES: Use un bolígrafo para completar el formulario. Por favor sombrear la opción mas apropiada o llene los espacios en blancos según sea necesario. Por favor sombrear solamente UNA de las opciones para cada pregunta, a menos que se especifique de otra manera.

La encuesta debe ser completada por el cuidador primario. El cuidador primario se define como el adulto responsable de coordinar el cuidado dental del niño, y que se identifica así mismo/a como tal. En este caso el cuidador primario puede ser uno de los padres, abuelo, tío, tía o custodio.

Cuando múltiples individuos son responsables por el cuidado del niño/a, se usará el individuo que se considera a el/ella mismo como el cuidador primario para los asuntos relacionados con la salud oral. Todas las referencias que se hagan del cuidador primario subsecuentemente asumirán esta definición.

1. ¿Qué relación tiene con el niño? (seleccione todos los que aplican)

☐ Padre/madre ☐ Custodio legal ☐ Abuelo/a ☐ Otro (Por favor especifique) _____

2. ¿Cuántos niños (menores de 18 años) viven en el hogar? Si no tiene ninguno, ponga cero.

3. ¿Tiene en su hogar niños que han sido diagnosticados con Trastornos del Espectro de Autismo?

☐ Si ☐ No (Gracias por su tiempo. Esta encuesta es sólo para hogares que tienen niños con autismo. Por favor, regrese lo papeles en el sobre de retorno.)

4. ¿Cuántos de sus hijos han sido diagnosticados con trastornos del espectro de autismo (ASD por sus siglas en ingles)? Escriba el número en la casilla

5. ¿Cuáles de los siguientes diagnósticos le han dado a su hijo/a? Si tiene más de un niño con ASD, responda de acuerdo con el niño mayor.

☐ Trastorno autista (autismo clásico) ☐ Trastorno de Asperger
☐ Trastorno dominante del desarrollo — sin que se dé otra especificación (PDD-NOS)

6. Si tiene más de un niño/a con ASD, ¿cuál es el diagnóstico de el niño/a que le sigue en edad?

☐ Solo un niño afectado – No se aplica ☐ Trastorno autista ☐ Trastorno de Asperger ☐ PDD-NOS

El resto de las preguntas se refieren a su hijo/a mayor con ASD - el niño/a que mencionó en la pregunta 5

7. ¿Cuál es la severidad del diagnostico de ASD en la actualidad? ☐ leve ☐ moderado ☐ severo ☐ no esta seguro/a

8. ¿Cual es la edad de su hijo?

años de edad (redondear a la edad más cercana)

9. ¿A qué edad fue diagnosticado su hijo/a con ASD?

años de edad (redondear a la edad más cercana)

10. Tiene su hijo alguna otra condición médica?

☐ No
☐ Si (Por favor especifique) _____

11. En la actualidad, ¿esta su hijo tomando algún medicamento que se le ha recetado?

- ☐ No
☐ Sí (Por favor escriba el nombre del medicamento y la razón por la que lo necesita)

12. ¿En el pasado, ha tomado su hijo algún (otro) medicamento que se le ha recetado?

- ☐ No
☐ Sí (Por favor escriba el nombre del medicamento y la razón por la que lo necesita)

13. ¿Se atiende su niño con un médico familiar para recibir cuidado médico?

- ☐ Sí ☐ No – POR FAVOR SALTE A LA PREGUNTA 15

14. ¿Por qué razón se atiende su niño con el médico familiar? ☐ Chequeos regulares ☐ Enfermedades solamente ☐ Ambos

15. ¿Está su hijo registrado en alguna de las siguientes organizaciones? Por favor seleccione TODAS las opciones que aplican

- ☐ Sociedad de Autismo de Carolina del Norte ☐ TEACCH
☐ Centro Clínico para el Estudio del Desarrollo y Aprendizaje
☐ Otro organización relacionada con la condición de ASD de su hijo (Por favor especifique:)

16. ¿Asiste su hijo/a a la escuela (incluyendo educación preescolar o pre-kinder)?

- ☐ SI ☐ No -POR FAVOR SALTE A LA PREGUNTA 18

17. ¿Qué servicios educativos recibe su hijo/a en la escuela? Por favor seleccione TODAS las opciones que aplican

- ☐ Ninguno ☐ Programa Educativo Personalizado ☐ Inclusión ☐ Especial
☐ Programa Comunitario Alternativo (CAP) ☐ Otro (Por favor especifique) _____

18. ¿Cuál es el nivel de educación de su hijo/a?

- ☐ Demasiado pequeño para ir a la escuela ☐ Preescolar o Jardín de Infancia ☐ 1ro al 3to grado
☐ 4to al 6to grado ☐ 7to al 9no grado ☐ 10mo al 12vo grado
☐ Se ha retirado de la escuela

19. ¿Dónde vive su hijo? ☐ En la casa ☐ Institución de cuidado ☐ Casa de Grupo ☐ Con la persona que lo cuida

20. ¿En qué tipo de comunidad vive su familia? ☐ Rural ☐ Suburbana ☐ Urbana / Ciudad

21. Describa su hogar:

- ☐ 2 padres ☐ Padre o madre soltero ☐ Parientes ☐ Otro (Por favor especifique) _____

22. ¿Cuál es el ingreso anual de su hogar?

- ☐ Menos de \$35,000 ☐ De \$35,000 a \$49,999 ☐ De \$50,000 a \$74,999 ☐ \$75,000 o más

23. ¿Qué tipo de seguro dental tiene su niño?

- ☐ Seguro Privado – ya sea ofrecido por medio de un empleador o una póliza familiar o individual que tenga por su cuenta
☐ Seguro Estatal - Medicaid/Health choice ☐ No tiene seguro

24. ¿Qué tipo de seguro médico tiene su niño?

- ☐ Seguro Privado – ya sea ofrecido por medio de su empleador o una póliza familiar o individual que tenga por su cuenta
☐ Seguro Estatal - Medicaid/Health choice ☐ No tiene seguro medico

25. ¿Cuál es su nivel de educación?

- ☐ No completó la escuela secundaria
☐ Graduado de secundaria o certificado de constancia de estudios secundarios o de preparatoria.
☐ Certificado de carrera de 2 años o algunos estudios universitarios (incluyendo colegios comunitarios y escuelas técnicas)
☐ Completó estudios universitarios
☐ Otros (Por favor especifique) _____

26. ¿Cuánto tiempo ha pasado desde la ultima vez que usted visitó al dentista?

- ☐ 6 meses o menos ☐ Mas de 6 meses, pero menos de un año
☐ Mas de un año, pero menos de 3 años ☐ Hace mas de 3 años
☐ Nunca ha ido ☐ No sabe/ no recuerda

27. ¿Existen dificultades en llevar a cabo los procedimientos de higiene dental del niño?

☐ Si ☐ No

28. En una escala del 1 al 10, ¿Qué tanto piensa usted, que su niño coopera con los procedimientos dentales?

no coopera en lo absoluto 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ muy cooperador

29. ¿Piensa usted que la salud oral es importante?

☐ Yes ☐ No

30. ¿En su opinión, cuál es el estado de la salud oral de su niño?

- ☐ Excelente ☐ Muy bueno ☐ Bueno ☐ Neutral ☐ Pobre ☐ No tiene dientes verdaderos

31. Durante los últimos 6 meses, ¿ha tenido su hijo dolor de dientes?

☐ Si ☐ No ☐ No sabe/ No recuerda

32. Durante los últimos 6 meses, ¿hubo alguna ocasión en que su hijo tuvo necesidad de recibir cuidado dental pero no pudo obtenerlo?

- ☐ Si ☐ No –POR FAVOR SALTE A LA PREGUNTA 34 ☐ No sabe/ No recuerda – POR FAVOR SALTE A LA PREGUNTA 34

33. La ultima vez que su hijo/a no obtuvo el cuidado dental que necesitaba, ¿cuáles fueron las razones principales por la que no pudo conseguirlo? (Por favor marque todas las opciones que apliquen)

- | | |
|---|--|
| <input type="radio"/> Falta de recursos necesarios para pagar | <input type="radio"/> No tenía seguro |
| <input type="radio"/> El dentista no acepta Medicaid/ seguro | <input type="radio"/> No hay dentista disponible |
| <input type="radio"/> No tuvo como llegar (problemas de transporte) | <input type="radio"/> Problemas de salud de otro miembro de la familia |
| <input type="radio"/> Tuvo otros asuntos familiares que atender | <input type="radio"/> Las horas no le convenían debido a su trabajo |
| <input type="radio"/> La espera es muy larga en la clínica /oficina | <input type="radio"/> Dificultad para conseguir cita |
| <input type="radio"/> No sabia a donde ir | <input type="radio"/> No le gusta/ confía/ cree en los dentistas |
| <input type="radio"/> Condición medica del paciente | <input type="radio"/> Habla un idioma diferente que el dentista |
| <input type="radio"/> Mi hijo/a no colabora | <input type="radio"/> Mi hijo/a es muy pequeño o joven |
| <input type="radio"/> Otra razón (Por favor especifique) _____ | |

34. Ha estado su hijo/a en el dentista alguna vez? ☐ No ☐ Si – POR FAVOR SALTE A LA PREGUNTA 36

35. Si su niño nunca ha recibido cuidados dentales, ¿cuáles son las razones principales por la que su niño nunca ha recibido cuidado dental? (Marque todas las opciones que aplican)

- | | |
|---|---|
| <input type="radio"/> No tiene los recursos necesarios para pagar | <input type="radio"/> No tiene seguro |
| <input type="radio"/> El dentista no acepta Medicaid / seguro | <input type="radio"/> No hay dentistas disponibles |
| <input type="radio"/> No tiene como llegar (problemas de transporte) | <input type="radio"/> La salud de otro miembro de la familia |
| <input type="radio"/> Hay otros asuntos familiares que atender | <input type="radio"/> Las horas no le convienen debido a su trabajo |
| <input type="radio"/> La espera es muy larga en la clínica / oficina | <input type="radio"/> Dificultad para conseguir citas |
| <input type="radio"/> No sabía donde ir | <input type="radio"/> Los dientes de leche se le van a caer por si solos muy pronto |
| <input type="radio"/> No le gusta/ confía/ cree en los dentistas | <input type="radio"/> La condición medica del paciente |
| <input type="radio"/> Habla un idioma diferente que el dentista | <input type="radio"/> Es probable que mi hijo no colabore |
| <input type="radio"/> Mi hijo/a es muy pequeño | |
| <input type="radio"/> La salud oral de mi niño es muy buena y no necesita ver al dentista | |
| <input type="radio"/> La condición dental de mi niño no es tan seria como para que lo tenga que ver un dentista | |
| <input type="radio"/> Otra razón (Por favor especifique) _____ | |

POR FAVOR SALTE A LA PREGUNTA 41

36. ¿Cuánto tiempo ha pasado desde la última vez que su niño visitó al dentista?

- | | |
|---|--|
| <input type="radio"/> 6 meses o menos | <input type="radio"/> Mas de 6 meses, pero menos de un año |
| <input type="radio"/> Mas de un año, pero menos de 3 años | <input type="radio"/> Hace mas de 3 años |
| <input type="radio"/> No sabe/ No recuerda | |

37. ¿Cuál fue la razón por la que su niño fue al dentista en su visita mas reciente?

- | | |
|---|--|
| <input type="radio"/> Chequeo, examen o limpieza | <input type="radio"/> Algo estaba mal, tenía molestias o dolor |
| <input type="radio"/> Fue para que le hicieran el tratamiento de alguna condición que el dentista descubrió en un chequeo o examen anterior | |
| <input type="radio"/> No sabe/ No recuerda Otro | <input type="radio"/> Otro (Por favor especifique) _____ |

38. ¿Cuál fue el problema principal que tuvo que afrontar durante la ultima visita de su niño al dentista? (Por favor marque todas las opciones que aplican)

- | | |
|--|--|
| <input type="radio"/> El Dentista y/o su asistente no pudo/pudieron controlar a mi niño | |
| <input type="radio"/> El dentista y su asistente no me trataron a mi o a mi niño con respeto | <input type="radio"/> El dentista no atiende niños pequeños regularmente |
| <input type="radio"/> El dentista no atiende a niños con necesidades especiales | <input type="radio"/> Mi hijo no pudo cooperar con el dentista |
| <input type="radio"/> El dentista no acepta el Medicaid | |
| <input type="radio"/> La clínica no esta equipada para atender a personas con necesidades especiales | |
| <input type="radio"/> Otra (Por favor especifique) _____ | |

39. ¿Qué tan seguido visita su niño al dentista?

- | | | | |
|--|------------------------------------|--------------------------------------|---|
| <input type="radio"/> Cada 3 meses | <input type="radio"/> Cada 6 meses | <input type="radio"/> Una vez al año | <input type="radio"/> Solo cuando tiene dolor |
| <input type="radio"/> Otro (Por favor especifique) _____ | | | |

40. ¿Qué tipo de clínica dental atiende a su niño para su cuidado dental?

- | | | | |
|--|---|---|---|
| <input type="radio"/> Dentista general | <input type="radio"/> Dentista Pediátrico | <input type="radio"/> Clínica Dental del Hospital | <input type="radio"/> Departamento de Salud |
| <input type="radio"/> Otro (Por favor especifique) _____ | | | |

41. ¿Cuál es el género de su hijo?

☐ Masculino☐ Femenino

42. ¿Cuál es el origen étnico de su hijo?

☐ Hispano o Latino☐ No Hispano o Latino

43. ¿Cuál es la raza de su hijo?

☐ Indio Americano / Nativo de Alaska☐ Asiático☐ Nativo de Hawai o de alguna Isla del Pacífico☐ Negro / Afro-americano☐ Blanco☐ Múltiples razas☐ Otro (Por favor especifique _____)

Gracias por su participación en esta encuesta.

Valoramos y apreciamos mucho su opinión para mejorar la accesibilidad a los servicios dentales para los niños. Por favor, envíenos la encuesta por correo en el sobre que hemos adjuntado.

Gracias!

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