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The Age and Primary Reason for the First Dental Visit in Children with Special Health Care Needs

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The Age and Primary Reason for the First Dental Visit in Children with Special Health Care Needs

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Dentistry at Virginia Commonwealth University.

By

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Abstract

THE AGE AND PRIMARY REASON FOR THE FIRST DENTAL VISIT IN CHILDREN WITH SPECIAL HEALTH CARE NEEDS

By: Amanda Dickerson Collie, DDS

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Purpose: The aim of this project is to evaluate the average age and primary reason for the first dental visit among patients with special health care needs as well as to examine socioeconomic factors and other barriers related to children with special health care needs accessing care.

Methods: This is a cross-sectional survey that was distributed to caregivers of children with special health care needs. Study data was collected through REDCap, a secure web-based survey application. The inclusion criteria for participating in the survey included having a child with a special health care need that presented for a recall or new patient examination. The survey was only formatted in English; any non-English speaking caregivers were excluded. The following demographics were ascertained in the survey: age and gender of the patient, level of education of the guardian, and household income.

Results: A total of 77 caregivers participated in the survey. Responses were summarized using counts and percentages. Associations with the child's age at the first dental visit were assessed using chi-squared or Fisher's exact tests. Only 13% of caregivers reported that their child was less than 1 by the time of their first dental visit. Most were between the ages of 1 and 3 (68%). Nearly all reported seeing a pediatric dentist for their first visit (89%) and that it was for a routine exam and cleaning (83%). Nearly half were self-referred (46%) but some reported being referred by their pediatrician (36%) or another specialist provider (10%). About one-third of guardians reported an experience where a dentist was unable to provide care for their child due to their SHCN (36%).

Conclusion: It appears that children with special health care needs (CSHCN) are establishing care with a pediatric dentist for routine care at an early age but caregivers of CSHCN are not

following the recommendation to have a first dental visit by the age of twelve months set forth by the American Academy of Pediatric Dentistry. Therefore, it is important to continue to educate caregivers of CSHCN on the importance of routine care as well as support general dentists in their role of caring for patients with SHCN.

Introduction

Children with Special Health Care Needs (CSHCN) face many challenges with obtaining proper medical and dental care. The American Academy of Pediatric Dentistry (AAPD) defines a special health care need (SHCN) as any physical, developmental, mental, sensory, behavioral, cognitive, emotional impairment, or limiting condition. These conditions require medical management, health care intervention, and/or use of specialized services or programs.[1] Children with special health care needs (CSHCN) can have conditions ranging from a behavioral issue such as autism spectrum disorder to systemic diseases like cancer or developmental disorders such as cerebral palsy. The National Survey of Children's Health conducted in 2019-2020 found that 19.4 percent or 14.1 million children living in the United Stated aged zero to seventeen have a SHCN; this survey showed an increase in the percentages of CSHCN that were reported in the 2009-2010 survey.[2,3] It is unclear if there is a greater number of CSHCN or if there is more awareness surrounding diagnosis and increased access to care.[3] The prevalence of CSHCN varies among sex, age, race, and income. The national survey found that boys were more likely to have a SHCN compared to girls and adolescents aged twelve to seventeen were the age group with the highest prevalence of SHCN compared to children aged zero to five and six to eleven.[3] The higher prevalence seen in older children could be due to conditions that may not be diagnosed or that do not develop until later in life.[3] Non-Hispanic black children and children from families with lower socioeconomic status also have a higher incidence of having a CSHCN.[2,3]

Medical and Dental Home

The concept of the dental home is derived from the medical home concept where children receive access to comprehensive, accessible, coordinated, and family-centered care.[3,4] A dental home allows the dentist to provide preventive services such as routine cleanings and fluoride application, as well as provide anticipatory guidance regarding home oral hygiene, diet, non-nutritive habits, and trauma. The medical home and the dental home each seek to provide continuity of care, specialist referrals, and preventive services as the patient develops from infancy to adolescence. Establishing a dental home develops a relationship between the patient, parent, and dentists that assists in managing the dental care of the patient. The American Academy of Pediatrics recommends that a child have an established medical home as does the AAPD. In 2019-2020, only 42.2 percent of CSHCN received care in a medical home.[2] Data analyzed from the 2016 National Survey of Children's Health found that CSHCN that do not have a medical home were more likely to be non-Hispanic from other racial and ethnic backgrounds, live in a family with two or more parents with at least one stepparent or single mother, and live in a family with a parent(s) that was educated at the high school level.[5] There is a very important relationship that exists between the medical and dental home. Children who have a dental home most likely also have a medical home. Those that have unmet medical needs also have unmet dental needs.[6] Due to this strong relationship, it is thought that families who are motivated to receive medical care are also motivated to find dental care for their children; although, this may be due to medical providers helping patients access dental care.[7] Nevertheless, a strong relationship between dental and medical colleagues is very important for families receiving dental care. The American Academy of Pediatrics recommends that

pediatricians or pediatric primary care physicians incorporate oral health screenings into their preventive visits. The periodicity schedule regarding preventive pediatric health care recommends that an oral exam should be given starting at six months.[8] The AAPD recommends that a child have their first dental visit by the age of one or within six months after the eruption of their first primary tooth.[4] In a survey sent out to pediatricians, only half of the pediatricians said that they examine the oral health of the majority of their zero to three year old patients.[9] The survey also found that only seventeen percent of pediatricians said that the first dental visit should occur by age one, while half of the respondents said that the first visit should occur by age three.[9] Pediatric primary providers play a vital role in recommending and encouraging families to seek out dental care as the relationship between the family and pediatrician is established early on in life. It is even more imperative for CSHCN to establish a dental home early on in order to promote a lifetime of good oral health due the elevated caries risk of this population.[10] Caregivers are often unaware of the age recommendation as they see the primary dentition as temporary, thus delaying the first dental visit until an easily apparent dental need such as caries, pain, or trauma occurs. Establishing a dental home early in life allows for the provision of necessary preventive care as well as education of caregivers about effective home oral hygiene habits with the goal of reducing restorative and emergency care in the future.

CSHCN and Oral Health

CSHCN are considered to be at a higher risk of developing oral health problems.[3,10] Oral health is an important component of one's overall health and well-being. Dental caries is the most prevalent disease of childhood and if left untreated can result in death in rare cases.[11] Oral pain and disease can affect a person's ability to eat, sleep, focus, and perform daily tasks. CSHCN may have limitations in their ability to care for their oral health; in addition, may also

have trouble expressing the discomfort or pain that they are experiencing. Some CSHCN may depend on a caregiver for oral hygiene due to developmental and neuromuscular delays and may also be orally averse and unreceptive to brushing and flossing at home. Many medications that are frequently taken to manage medical conditions can cause xerostomia, are high in sugar or, in the case of seizure medications, may cause gingival overgrowth.[12] CSHCN, especially those with autism spectrum disorder, may have oral aversions or hypersensitivities to texture, color, and taste limiting their diet.[13] All of these factors contribute to CSHCN having a higher risk of developing oral disease and likely requiring dental care that is specialized and multidisciplinary.[12] Oral health conditions and diseases that are commonly associated with CSHCN include: buildup of calculus leading to increased risk of gingivitis and periodontal disease, enamel hypoplasia, dental caries, oral aversions and behavior problems, dental crowding, malocclusion, anomalies in tooth development and arch formation, bruxism and wear facets, fracture of teeth, and trauma.[14] For individuals without SHCN, these conditions may seem relatively manageable and treatable, but for CSHCN these oral diseases can have overwhelming and potentially devastating effects to children suffering from compromised immunity or cardiac conditions.[14] Due to the susceptibility of CSHCN to oral diseases, the AAPD recommends that preventive care guidelines be tailored to fit the oral health care needs of CSHCN.[15] Preventive care may include, but is not limited to, an oral exam, caries risk assessment, radiographic examination, prophylaxis and topical fluoride, anticipatory guidance, oral hygiene and dietary counseling, and assessment of oral growth and development. In a recent study published in 2021, using data from the National Survey of Children's Health, it was found that a higher proportion of CSHCN compared to children without SHCN received a preventive dental care visit, but CSHCN had higher rates of oral health problems.[16] Preventive dental care

starting at an early age in CSHCN allows the dentist to monitor oral health and incorporate preventive care approaches through the use of sealants, fluoride, and silver diamine fluoride. Preventive dental visits also allow caregivers to seek advice regarding home oral hygiene as well as give an opportunity for the child to become more comfortable with the dental home.

Barriers to Dental Care

CSHCN face many challenges in receiving dental care and treatment. The five barriers that McIver describes for CSHCN include: 1) the primary medical system; 2) parents of the child; 3) the child; 4) the dentist; and 5) payment for care.[17] The ability for a family to access and receive care also depends on insurance coverage, cost, geographical location, the severity or complexity of the SHCN, as well as the experience of the provider with caring for individuals with SHCN. Nelson et al found that the top three perceived barriers to dental care for families with CSHCN included: 1) "dental care is too expensive"; 2) "hard to find a dentist willing to treat"; and 3) "child's medical condition makes dental treatment very complicated".[18]

Insurance often plays a major and crucial role in access to care especially for CSHCN. The most common reason for CSHCN not receiving preventive dental care is due to cost and lack of insurance.[7] Uninsured children are more likely to skip regular preventive visits and have worse oral health.[5,19] CSHCN account for forty-two percent of total medical expenditures in the United States, most likely due to frequent appointments with health care providers.[20] A study conducted in Ohio that compared oral health outcomes among CSHCN with Medicaid and private insurance, found that the Medicaid population had higher unmet dental care needs and worse oral health.[20] Although Medicaid will cover preventive dental visits and cover comprehensive dental needs, many CSHCN that have Medicaid have unmet preventive dental

care.[21] This could be due to the number of dentists available to treat patients that take Medicaid as well as the low reimbursements for dental procedures with Medicaid.[21]

For many caregivers, finding a dental home and provider willing to treat their child can be difficult. CSHCN with a greater severity such as Trisomy 21, Cerebral Palsy, developmental delay, and autism spectrum disorder experience greater difficulty in receiving dental care.[7,18] The severity or complexity of the diagnosis may play a role in the dental practitioner's willingness and comfortability in treating a child with a SHCN. Patients with SHCN often have dental treatment completed under general anesthesia or sedation due to behavioral challenges. Families that have CSHCN may have limited access to providers that offer these advanced behavior guidance techniques.

Families with CSHCN that live in rural areas may have difficulty finding a provider primarily due to geographical limitations. In a study that looked at the effect of rural residence on dental unmet need for CSHCN, it was found that these patients had a higher unmet dental need due to difficulty accessing care.[22] CSHCN that are in more rural areas are also more likely to be insured by Medicaid and experience significant financial strain also contributing to the unmet dental care.[22] Overall, CSHCN are limited in their access to adequate dental care due to barriers including geographical limitations, challenges with insurance and payment for dental care, behavior of the patient, and extent of their treatment needs.

Dental School Training and Residency Programs

Pediatric dental residency programs are a primary resource where CSHCN receive dental care and provide a unique opportunity for residents to develop the skills to better treat and serve CSHCN.[23] Pediatric dental residents receive advanced training in providing dental care under

general anesthesia or with sedation as well as other behavior guidance techniques. In a national survey conducted in 2001, Casamassimo et al found that only ten percent of general dentists see CSHCN often or very often, and only one in four dentists had "hands-on" experience with patients with SHCN in dental school.[24] Since 2006, the Commission on Dental Accreditation (CODA) requires that dental students "must be competent in assessing the treatment needs of patients with special needs".[24] Although the CODA requirement has been implemented, many new dentists still feel they received inadequate and insufficient exposure to treating patients with SHCN.[24] Patients with SHCN are often more challenging to care for from a behavioral and medical perspective and it usually requires additional time and resources to provide dental care to these patients.[23] Also, finding a general dentist willing to treat CSHCN and that accepts Medicaid insurance can be very challenging for families.[25] There are only 8,400 practicing pediatric dentists in the United States, making general dentists needed in providing care to patients with SHCN.[16,26] With the increasing number of CSHCN, it is important that dental education place an emphasis on providing students with didactic and clinical experience in special care dentistry.

The purpose of this research study is to conduct a survey among caregivers of CSHCN and evaluate the age of their first dental visit and the primary reason for that visit. There have been several studies that have surveyed caregivers of healthy children and there is a consensus that the majority of children did not have their first dental appointment by their first birthday. In a study conducted in India, approximately half of the patients surveyed (n=4543) had their first dental visit after the age of five.[27] Studies in Poland[28], Brazil[29], and Saudi Arabia[30] also revealed that the first dental visit ranged between the ages of three and six. The most common reason for the first dental visit among all of these studies was due to dental pain or dental caries.[27–31] These

studies failed to include or distinguish whether having a SHCN influenced the timing and reason for the first dental visit. This survey sought to examine the knowledge of caregivers of CSHCN in regards to their first dental visit through a questionnaire, taking into account the child's healthcare diagnosis and sociodemographic details.

Methods

This study was granted exempt status from the Virginia Commonwealth University (VCU) Institutional Review Board HM 20023973. This was a cross-sectional study to determine the age and primary reason for the first dental visit for patients with SHCN. Study data was collected and managed using Research Electronic Data Capture (REDCap) tools hosted at VCU. REDCap is a secure, web-based software platform designed to support data capture for research studies.[32] This survey was formulated by clinicians and given by the dental provider to the parent/guardian of a patient with a SHCN.

Parents/legal guardians of patients with SHCN who presented to VCU Department of Pediatric Dentistry for a dental appointment were included in the study. Two locations were included in this study: patients that attended dental appointments at the dental clinic located in the Children's Hospital of Richmond (CHoR) at VCU and a satellite clinic of CHoR approximately ten minutes from the hospital. If this was the first dental visit for the patient, the patient was identified while reviewing their medical history. For patients of record at CHoR, Axium (Exan, Las Vegas, NV), which is an electronic dental software, was used to identify when a patient with a SCHN came in for an appointment. At the satellite clinic, Epic (Epic Systems, Madison, WI), which is an electronic medical record system used by the health system, screened patients with SHCN at this location. The medical and dental electronic health records were only used as a screening tool to identify potential participants. The information gathered from the electronic record about the child or guardian was not collected or documented in any format. The survey was distributed by any of the first or second year pediatric dental residents that

identified a patient that met the inclusion criteria. Participation was voluntary and not every parent/guardian of a child with SHCN took the survey.

A total of twenty-two questions were asked in the survey, but none of the questions were mandatory. The data collected was completed anonymously without a way to link to any identifiers. Caregivers had the opportunity to complete the survey privately through REDCap. All patients with SHCN at VCU Pediatric Dentistry were seen in private rooms that limit any interactions with other patients in the clinic. The survey questions targeted guardian demographics, the patient's demographics, and questions centered around the child's SHCN. The following parent/guardian demographics were collected in the survey: level of education, family income level, and hours worked during the week. Caregivers were also asked to note how often they see their own dentist for a routine dental exam. The survey was only formatted in English and any non-English speaking caregivers were excluded. Caregivers that completed the survey were given a five-dollar Amazon gift card sent to the email address they provided.

Responses were summarized using counts and percentages. Associations with the child's age at the first dental visit were assessed using chi-squared or Fisher's exact tests. Significance level was set at 0.05. SAS EG v.8.2 (SAS Institute, Cary, NC) and was used for all analyses. Recruitment occurred during a six-month time frame to avoid recruiting the same subjects returning for their routine follow-up.

Results

A total of 77 caregivers participated in the survey. The majority reported an annual income of less than $50,000 (61%), working less than 40 hours a week (70%), and did not receive higher than an associate's degree (78%). Respondent demographics are provided in Table 1.

Table 1: Parent/Guardian Respondent Demographics

	n	%
Guardian's Education		
Less than High School	10	13%
High School diploma	34	45%
Associate's degree	15	20%
Bachelor's Degree	11	14%
Graduate or Postgraduate	6	8%
Annual Income		
< 25,000	19	25%
25,000-49,999	27	36%
50,000-74,999	7	9%
75,0000-99,999	4	5%
>100,000	19	25%
Work Hours Per Week		
0-10	33	45%
20-25	4	5%
25-40	14	19%
>40	22	30%
Parent/Guardian's frequency of dental visits		
Every 6 months	55	73%
Once a year	11	15%
When I have a problem	9	12%

Demographics of the children represented by the responding caregivers are provided in Table 2. Most of the children were greater than 8 years old (80%), lived at home (96%), 61% were male, 53% reported diagnosis of autism spectrum disorder, and 28% required use of a wheelchair or other mobility device.

Table 2: Demographics of Patients

	n	%
Child's Age		
3-5 years	6	8%
6-8 years	9	12%
>8 years	60	80%
Child's Gender		
Male	46	61%
Female	30	39%
Child's Living Arrangements		
Lives with parent or guardian	72	96%
Lives in a group home	2	3%
Other	1	1%
Child's Communication		
Unable to Communicate	21	28%
Some Difficulty	29	39%
No Difficulty	24	32%
Diagnoses		
Autism Spectrum Disorder	40	53%
Attention-Deficit/Hyperactivity Disorder	18	24%
Down Syndrome	5	7%
Cerebral Palsy	14	18%
Intellectual Disability	26	34%
Other	21	28%
Mobility Device Use		
Yes	21	28%
No	53	72%
Specialty Providers		
Cardiologist	15	20%
Neurologist	38	50%
Pulmonologist	10	13%
Nephrologist	7	9%
Other	33	43%
Who Brushes Child's Teeth		
Yes-- I or another parent/guardian brushes their teeth	39	53%
They receive help with brushing their teeth	14	19%
No, they brush on their own	20	27%
Times Brushed per Day		
1	28	38%
2	44	59%
Other	2	3%
Child's Appointment Frequency		
Yes, they have a cleaning and exam every 6 months	62	83%
No, they have a cleaning and exam every year	5	7%
Other	8	11%

Only thirteen percent of caregivers reported that their child was less than one year old by the time of their first dental visit. Most were between the ages of one and three (68%). Nearly all reported seeing a pediatric dentist for their first visit (89%) and the primary reason was for a routine exam and cleaning (83%). Nearly half were self-referred (46%) but 36% reported being referred by their pediatrician or other specialist provider (10%). Summary of responses related to the child's first dental visit are provided in Table 3.

Table 3: Child's First Dental Visit Summary

	n	%
Age at First Dental Visit		
Less than 1 years old	10	13%
1-3 years old	51	68%
3-5 years old	9	12%
Greater than 5 years old	5	7%
Type of Provider for First Visit		
Pediatric Dentist	67	89%
General Dentist	7	9%
Other	1	1%
Reason for First Visit		
Exam and Cleaning/Routine Check up	62	83%
Cavities	4	5%
Pain	1	1%
Trauma	1	1%
Other	7	9%
Who Referred you for First Visit?		
Pediatrician	26	36%
Specialist Doctor	7	10%
I was not referred/self-referred	33	46%
Other	6	8%

A summary of potential barriers to dental treatment are provided in Table 4. Just over a third of respondents reported having been to a dentist previously who was unable to treat their child due to their special health care needs (n=26, 36%). When asked about potential barriers to having their child treated, 33% indicated their child's special health care needs, 15% indicated the parents' working schedules, and 10% reported the lack of a dental office nearby. Almost half reported they have not experienced any barriers so far (47%). Eighty-nine percent of caregivers indicated they provide transportation for their child's dental visits.

Table 4: Barrier to Dental Care for Patients with Special Health Care Needs

	n	%
Have you ever been to a dentist previously who was unable to treat your child due to special health care needs?		
Yes	26	36%
No	47	64%
Barriers		
Working parents	11	15%
Length of visit	2	3%
Appointment time too far in future	4	5%
No dental office nearby	7	10%
Cost of treatment	3	4%
My child will not cooperate/too young	9	12%
My child has special health care needs	24	33%
No issues so far	34	47%
Transportation for Dental Visits		
Parent or Guardian	66	89%
Group Home or Medicaid	8	11%

Whether or not a child was seen by a dentist by the age of three was significantly associated with the type of provider they saw for their first visit, such as a pediatric dentist (p=0.0046), whether or not they experienced a failed dental visit (p=0.0185), and their belief regarding when the first visit should be (p=0.0004) (Table 5). Children who had their first dental visit by the age of three were most commonly treated by a pediatric dentist (89%) compared to 64% of those who didn't see the dentist until age three. Only 5% of patients seen before age

three were treated by a general dentist compared to 29% of those seen age three or older. For children with special health care needs, when asked if they had been to a dentist and unable to receive treatment, 50% of children who were not seen before the age of three responded yes compared to 32% of those who were seen before the age of three. The other factor associated with the age at the first dental visit was the parent's belief about the age when the first visit should occur. For children seen by the age of three, 43% indicated by the age of one and 35% responded when all the baby teeth were present. For children seen at age three and older, only 7% indicated by the age of one and 40% indicated when all the primary teeth are present. Further, a third of caregivers whose child's first visit was three or older indicated the first visit should occur at age five years or older compared to just 2% of those who were treated earlier. Age at first dental visit was not significantly associated with the reason for the first dental visit ($p=0.2804$), the referring provider ($p=0.5802$), the parent's frequency of dental visits ($p=0.5232$), or the transportation method for dental visits ($p=0.3585$).

Table 5: Factors Associated with Age of First Dental Visit

	Before 3	After 3	P-value
Type of Provider for First Visit			0.0046
Pediatric Dentist	58, 95%	9, 64%	
General Dentist	3, 5%	4, 29%	
Other	0, 0%	1, 7%	
Reason for First Visit			0.2804
Exam and Cleaning/Routine Check up	49, 80%	15, 94%	
Problem (Caries, Pain, Trauma, etc)	12, 20%	1, 6%	
Who Referred you for First Visit?			0.5802
Provider (Pediatrician or Specialist)	27, 47%	6, 38%	
I was not referred/self-referred	31, 53%	10, 63%	
Experienced Failed Visit			0.0185
Yes	19, 32%	7, 50%	
No	40, 68%	7, 50%	
When should the first visit be?			0.0004
When my child has all of their baby teeth	21, 35%	6, 40%	
1 years old	26, 43%	1, 7%	
2 years old	12, 20%	3, 20%	
5 years or older	1, 2%	5, 33%	
Parent/Guardian's frequency of dental visits			0.5232
Every 6 months	41, 69%	14, 88%	
Once a year	10, 17%	1, 6%	
When I have a problem	8, 14%	1, 6%	
Transportation for Dental Visits			0.3585
Parent or Guardian	53, 91%	13, 81%	
Group Home or Medicaid	5, 9%	3, 19%	

Discussion

This study sought to investigate challenges related to Children with Special Health Care Needs (CSHCN) accessing dental care as well as the age and primary reason for the first dental visit. The majority of participants who participated in the survey reported a lower-income and lower level of education, but reported seeing their own dentist routinely every six months. All the participants in this survey were a parent/guardian of a CSHCN. Caregivers of children with autism spectrum disorder and intellectual disabilities made up most of the sample population. Overall, the findings of this research were positive regarding the first dental visit in CSHCN.

Primary Reason for the First Dental Visit

The majority of caregivers of CSHCN reported that the first dental visit for their child was for a routine cleaning and/or exam (83%). Beil et al compared the likelihood of children with and without SHCN, and it was found that there was no difference in dental care utilization or dental care expenditure between these two populations.[33] Whether or not CSHCN use preventive care services with greater or less frequency than children without SHCN is still being investigated. Craig et al found that CSHCN are less likely to use preventive dental services.[25] In contrast, Cleave et al found that rates of preventive dental visits were higher in CSHCN.[34] Although it was encouraging that the majority of respondents in this study appear to be seeking out preventive dental care at an early age, more research is needed to determine if there is a difference in preventive dental care between children with and without SHCN and reasons for this difference. This study among CSHCN found only one percent reported that the first dental visit was due to trauma. Although there have been some studies that have found that dental trauma is greater in CSHCN, trauma is more likely to take place at an older age when the child is in permanent dentition making it unlikely that dental trauma is a reason for a first dental visit.[35,36]

Primary Reason and Oral Health

This study was conducted in a hospital setting where many of the patients receive not only their dental care but also receive primary medical and specialty care. Patients seen in this setting may see the value in preventive care more so due to the coordination of the medical and dental team as well as the proximity of the dental clinic to other medical specialties. Clinicians who practice in an academic and/or hospital environment may be more likely to be educated on the dental needs of patients with SHCN and the importance of an early referral to a dental provider. These practitioners may also be more knowledgeable about the AAPD recommendation for age of the first dental visit compared to clinicians in a private practice or rural setting. In addition to routine cleaning and exams, caregivers of CSHCN may be seeking guidance on home oral hygiene strategies. The results of this study showed that over half of caregivers reported that their child with SHCN brushes two times per day (59%) and receives help with brushing their teeth (53%). As many CSHCN have limitations with dexterity and motor coordination, it is important for caregivers to engage in daily oral hygiene practices. Caregivers should be reminded at every dental visit about the importance of brushing twice daily and using a fluoridated dentifrice. For patients who may exhibit intolerance to the taste and texture of toothpaste, a toothpaste without sodium lauryl sulfate has been recommended.[14] There are also toothbrushes with modifications that caregivers can use at home in order to increase compliance. Regardless, it has been found that CSCHN have a higher rate of oral health problems compared to children without SHCN.[16] Therefore, preventive oral care is essential to maintain oral health.

Primary Age of the First Dental Visit

The majority of caregivers in this study reported that their child's first dental visit was between the ages of one to three (68%), while a minority reported the first dental visit was by the child's first birthday (13%). Although the majority of caregivers with SHCN are attending a first dental visit before the age of three, the AAPD recommends the first dental visit by the age of one.[4] Caregivers who took their child to the dentist by the age of three were more likely to see a pediatric dentist and 43% answered correctly regarding the recommendation that they should be seen by the age of one. This result was unexpected because it was hypothesized that CSHCN would not attend a dental visit until they were older as well as that their caregivers would not be aware of the recommendation set forth by the AAPD. Again, access to a pediatric dental facility in close proximity to other specialty providers serving CSHCN may have influenced the results.

Referral Source

Although many CSHCN experience a greater number of visits with medical providers, most caregivers reported they were not referred by a pediatrician or other specialty provider. This supports the findings of previous studies conducted among pediatricians and illustrates their lack of training in oral health care. A study published in the *Journal of Family Medicine and Primary Care* found that only about one-fifth of pediatricians always perform an oral health examination of CSHCN during their general health examination.[37] This study also found that only about one-fourth of pediatricians refer to an oral health provider for their patients with SHCN who have oral disease.[37] Indira et al found that most pediatricians do agree that it is important to conduct an oral health examination by the age of one and that is important for the medical and dental team to work together.[38] Pediatricians are in a unique position to identify dental problems early, provide education to the caregivers regarding oral healthcare, and make

referrals to dental providers at the recommended time frame set forth by the AAPD. Therefore, pediatricians have the opportunity to play a vital role in the management and care of CSHCN receiving oral health care.

Barriers to Dental Care

CSHCN face many barriers surrounding their first dental visit, which include having working caregivers, length of the appointment, not being able to schedule an appointment within a reasonable time frame, cost of treatment, not having access to a dental office nearby, having a child who cannot cooperate, and/or having a child with a SHCN. About one-third of caregivers responded that a barrier to receiving dental care was that their child has SHCN, and about one-third of respondents said that they had previously been to a dentist who was unable to treat their child because of their SHCN. Dental appointments for CSHCN often require a private room, additional team members, and a longer period of time spent with the dentist. For many general dental practitioners, they may not have the staff or space to accommodate CSHCN. Due to these challenges, many pediatric dentists continue to provide care to CSHCN through adolescence and young adulthood.

Dental Care Transition

CSHCN are living longer with chronic diseases as a result of medical advances and are requiring oral and medical care into adulthood.[12] Transitioning CSHCN to an adult dental home is going to continue to be a challenging endeavor. Several organizations, including the AAPD, have put together a policy statement to improve the health care transition for patients with SHCN. The AAPD recommends that the transition should take place at a time agreed upon by the patient, parent, and pediatric dentist, to a dentist who is knowledgeable and comfortable with

treating the patient.[26] As CSHCN transition into permanent dentition, often their dental needs become outside the scope of a pediatric dentist. In an adult patient with SHCN, dental treatment needs may often require a general dentist or other specialty dentist such as an endodontist, periodontist, or oral surgeon. For this reason, general dentists and other specialty providers should be prepared to take over the care of the adult patient with SHCN.

Limitations and Future Research

This study presented several limitations including the sample size and language of the survey. This survey had a total of seventy-seven participants across six months of data collection. The hospital clinic sees approximately five to ten patients with SHCN each week, while the satellite clinic sees approximately four to seven patients with SHCN each week. Prior to data collection, the estimated response was one-hundred responses, but once data collection started this estimation turned out to be rather high. Dental appointments for CSHCN are scheduled longer than the actual appointment time as a result of deteriorating patient behavior and the parent's need to end the appointment sooner. For this reason, many of the caregivers who did complete the survey had a child who was fairly cooperative in the dental chair, possibly influencing the overall results of the study. Another limitation of this study was that it was only conducted in English. The patient population at VCU Pediatric Dentistry includes many non-English speaking individuals and many were excluded from representation in the study.

This survey was given to any caregivers of a CSHCN regardless if this was their first visit to the dentist. The caregivers completing this survey may have been subject to recall or obsequiousness bias. The majority of caregivers reported that their child was greater than eight years old (80%) and had their first dental visit before age three (81%). This study required that caregivers recall the age at when their child's first dental visit was and details surrounding that

appointment; however, this information may have been recalled from many years ago depending on the age of their child at the appointment. This survey may also have been affected by obsequiousness bias, which is when the respondent answers in a way perceived to be desired by the investigator. Given these limitations, future research should include administering the survey only at the very first dental visit of CSHCN, translating the survey to include Spanish speaking caregivers, increasing the sample size, and surveying caregivers of CSHCN who may not have a dental home.

Conclusion

Overall, it appears that CSHCN are establishing a dental home with a pediatric dentist for routine care at an early age. These findings suggest that caregivers of CSHCN are following the recommendation set forth by the AAPD. CSHCN who have established a dental home at an early age appear to be more likely to see a pediatric dentist, understand the recommended guidelines, and are less likely to encounter a dentist that is unable to provide care due to a SHCN. However, as the number and prevalence of CSHCN increases, it is vital to continue to educate caregivers on the importance of routine examinations as well as support general dentists and other health care providers in their role of caring for patients with SHCN. CSHCN will continue to face unmet dental needs if barriers to care are not overcome. While most caregivers in this study reported that they had not experienced any issues thus far, a significant number reported that a barrier to receiving dental care was having a child with a SHCN. Decreasing financial, geographical, and social barriers as well as providing a coordinated transition from the pediatric dentist to the adult dentist are critical factors for improving the oral health of CSHCN.

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