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Publication Date

2023

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Understanding Barriers to Dental Care for Children with Special Health Care Needs


by
Alain Flores


THESIS
Submitted in partial satisfaction of the requirements for degree of
MASTER OF SCIENCE

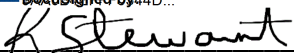
in
Oral and Craniofacial Sciences

in the
GRADUATE DIVISION
of the
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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ACKNOWLEDGEMENTS

Thank you to Dr. George Taylor, DMD, MPH, DrPH and Dr. Kristin Hoeft, PhD, MPH for their contribution to the formulation of study design.

This study was supported by the University of California San Francisco Population Health and Health Equity Scholars pilot award. This project was also supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$175,205 with 0% percentage financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

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ABSTRACT

Alain Flores: Understanding Barriers to Dental Care for Children with Special Health Care Needs

Purpose: The aim of this mixed method study was to identify barriers for children with special health care needs (SHCN) to receiving routine preventive dental care following dental care with general anesthesia (GA).

Methods: Electronic health records were reviewed for inclusion criteria and demographic data. Caregivers of children with SHCN were contacted to participate in qualitative interviews. Interview topics explored child, family, and community level influences to accessing dental care. Qualitative analysis identified key themes of barriers and enablers to care.

Results: A total of 1,708 children received dental care with GA during the two-year study period, of which 498 (29.16%) had a diagnosis of a SHCN. The most common type of SHCN was neurodevelopmental disorders (n=142, 28.51%). The mean age at time of GA was 8.6 years. Fifty caregivers completed interviews. Identified barriers to obtaining routine dental care included child stress/anxiety, finding an accepting provider, dismissive providers, and proximity of provider/transportation to dental care. Enablers to obtaining care included effective behavior management, continuity of provider/care, positive provider attitude, and referral to an accepting provider.

Conclusion: Adequately trained and local providers with an accepting attitude are essential to enabling children with SHCN to obtain equitable access to routine preventive dental care.

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Introduction:

Children with special healthcare needs (SHCN), including physical, intellectual, and developmental disabilities, experience a disproportionate level of oral disease that is exacerbated by increased barriers to and inequitable access to routine preventive dental care. Providing access to preventive dental care to children with SHCN is an imperative step in improving and maintaining their overall health. In California, an estimated 10% to 20% of individuals under age 21 have SHCN, which commonly stem from attention deficit disorder, developmental delay, anxiety, and autism. ^{i, ii}

A known occurrence in children with SHCN is an increased risk of dental caries and a decreased prevalence of having a dental home, - defined as “an ongoing relationship between the dentist and the patient, inclusive of all aspects of oral health care delivered in a comprehensive, continuously accessible, coordinated, and family-centered way.” ^{iii, iv, v} Disappointingly, despite the increased risk and prevalence of dental disease in the pediatric SHCN population, the utilization of preventive dental care in individuals with SHCN is lower than it is in those without SHCN. ^{vi}

Additionally, many children and adolescents with SHCN receive dental treatment with general anesthesia (GA). While children with SHCN may have medical and behavioral indications for dental treatment with GA, it is also the most medically invasive and costly method of providing dental treatment. ^{vii} Furthermore, dental treatment with GA is not an effective method of reducing oral disease. Greater than three-fourths of children with SHCN develop new dental caries within a year after treatment. ^{viii} Children with SHCN who do not access routine dental care following treatment with GA, are four times as likely to require additional dental treatment with GA in the future. ^{ix}

Understanding that dental caries is a multifactorial disease^{ix} and additionally knowing that social determinants of health^x are inextricably tied to the oral health of all children, this faulty healthcare model wherein children with SHCN are; 1) at increased risk for dental caries, 2) have greater barriers to obtaining preventive dental care, and 3) disproportionately experience GA for dental care, is apt for intervention at the patient and population level to reduce and prevent dental disease and increase oral health equity.

The aim of this study was to identify barriers and enablers for the population of children with SHCN to receiving routine preventive dental care following dental treatment with GA.

Methods:

This study used a retrospective mixed methods qualitative-quantitative design. Inclusion criteria for this study included children with SHCN who had dental treatment with GA at the University of California, San Francisco from January 1, 2016, through December 31, 2017, and their parents/guardians/caregivers. SHCN was defined as any physical, developmental, mental, sensory, behavioral, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or use of specialized services or programs.^{xi} This study was approved by the Institutional Review Board of the University of California, San Francisco (IRB #21-34319).

Quantitative methods:

A retrospective review of electronic health records was completed for children with SHCN who received dental treatment with GA at UCSF from January 1, 2016 through December 31, 2017. An inclusion period of approximately five years prior to study initiation was purposively selected, to analyze patients return for dental care over a substantial duration following dental care with GA. Data that was extracted from these records included dental, medical, and demographic variables. Dental variables of interest that were collected included the date of GA, whether the patient returned to UCSF pediatric dental clinic at any point in time after GA, the date of the first visit to UCSF after their dental care with GA (if any), the most recent visit to UCSF dental clinic post GA (if any), and total number of visits to UCSF dental clinic post GA (if any). Medical variables collected in the chart review included the medical diagnosis. These diagnoses were categorized into one of 11 major categories of SHCN (See Table 1).

Demographic information collected included primary language spoken at home, birthdate, and home zip code.

Qualitative methods:

Parents/guardians of children with SHCN who met the inclusion criteria were contacted by study personnel to participate in qualitative interviews for this study. Individuals to recruit for the qualitative interviews were randomly identified from the list of patients in the quantitative chart review. Purposeful sampling was used to identify individuals who spoke different languages at home, with the goal of interviewing a group of individuals that would be representative of the languages spoken in the larger sample. Recruitment and consent were completed verbally using a pre-determined script. Interviews were conducted in English and Spanish by study personnel, a telephone interpreter was used to complete interviews in Cantonese. All interviews were recorded, transcribed and translated if needed.

Each interview consisted of a series of open-ended questions related to the parents/guardian's experience in obtaining dental care for their child with SHCN. The questions allowed for a natural conversation about their child's experience at the dentist, as well as the parent/guardian's experience taking their child to the dentist. Although there was an interview script of open-ended questions, the conversation was allowed to flow, and the parent/guardian would often steer the conversation based on their perspective and personal and family experiences. Topics explored included child, family, and community level influences to accessing healthcare, such as physical attributes, insurance, social support, transportation, cultural beliefs, health behaviors, health system characteristics and other influences as described by the social determinants of oral health model.^{xi} Furthermore, parents/guardians were asked to provide insight into what they believe would be most impactful and supportive in maintaining access to care and good oral health for children with SHCN.

Data analysis:

For the retrospective chart review, descriptive statistics for demographic variables were completed. Further statistical analysis and descriptive statistics were completed on this larger sample for proportion and frequency for which patients returned for routine preventive visits following treatment.

An open-coding qualitative analysis was used to analyze the responses of the interview participants. Key themes of enablers and barriers to maintaining a dental home and accessing routine preventive dental care were identified. Qualitative analysis software was used to identify and apply thematic coding to all interview transcripts.

Results:

From January 1, 2016 to December 31, 2017, there were a total of 1,708 children treated with GA by UCSF pediatric dentistry. Of those cases, 498 (29.16%) were children with SHCN that met the inclusion criteria for this study. Prevalence of SHCN by category are shown in Table 1, with Autism Spectrum Disorder/Neurodevelopmental Disorder being most prevalent.

The mean age of the patients at the time of dental treatment with GA was 8.6 years (SD 6.64). The mean age of the patients at the time of the retrospective chart review was 14.5 years (SD 6.68). The primary language of the families spoken at home were: English (384, 77.11%), Spanish (70, 14.06%), Chinese (7, 1.41%), Other (7, 1.41%), and Unknown (30, 6.02%). Some patient records did not designate the primary language spoken at home. Those patients were recorded as “Unknown” for language spoken at home. On average, families lived 65.8 (SD 55.75) miles from UCSF.

About two thirds of patients (66.4%) returned to UCSF for at least one dental visit of any kind after their dental treatment with GA. Overall, patients did not return frequently or routinely for preventive dental visits following dental treatment with GA. On average, patients did not return to UCSF for their first visit following treatment with GA until about 1.5 years (mean days 526.2, SD 409.43) after the date of GA for dental treatment. On average, patients returned for dental visits at UCSF about every

nine months following GA (sum of total visits during study period divided by total months in study period mean=8.9 (SD 9.22)).

Fifty interviews were conducted with parents/guardians of patients with SHCN. The breakdown of the SHCN categories for the interviewed families are shown in Table 1.

Several themes about accessing dental care emerged through qualitative analysis of interviews conducted with parents/guardians. Identified themes were categorized as a barrier or enabler to their child with SHCN finding and maintaining a dental home. Key barrier themes identified included: (1) Child stress/anxiety; (2) Finding an accepting provider; (3) Provider rapport: Dismissive; and (4) Proximity of provider/Transportation. Major enabler themes identified included: (1) Effective behavior management; (2) Continuity of provider/care; (3) Provider rapport: Positive attitude; and (4) Referral to an accepting provider. Each of the themes are described below.

Barriers:

Child stress/anxiety:

A primary theme that emerged as a barrier to a child maintaining a dental home was the stress and anxiety that a child feels surrounding a dental visit, often times related to past negative experiences at a dental office. Although examples of child stress and anxiety during exams were plentiful, many families also noted that negative reactions for their children could also occur even before they arrived at the dental office.

“He doesn’t usually want to go. I have to talk to him and calm him down. Sometimes I let him sit in the front seat, but then those days I won’t, because he’ll get upset and sometimes, he’ll swing his arms and I’m driving. So I can’t have him in the front, I have to put him in the back seat. He’s like, no, I don’t want to go.”

According to the families, the level of stress and anxiety often increases once their child enters the office or exam room.

“He kicks, he throws himself on the floor. He starts kicking his head with his fists or hitting his head against the floor or the wall ... Because when we are coming in the building, he starts crying, and

whining, but he's able to come in. We have to physically hold him in order to get him in. He doesn't walk because he wants to run back to the car."

The parents see their child in distress, and they perceive the often-traumatic experience of going to the dental office as a barrier to maintaining routine dental visits.

Finding an accepting provider:

For a majority of the families interviewed, a major barrier to regular dental care for their child was finding an accepting provider. Even for the families who currently had a dental home, most had struggled to find a dentist at one point in their child's life. There were two main reasons that parents had difficulties finding a dental home for their child. The first was that certain providers refused to see their child due to their medical history. The second was that parents reported providers were not properly trained to treat their child.

"So we really couldn't find a dentist that wanted to see [my son]. He's non-verbal. He doesn't really follow instructions. Mentally, he's about nine months old and he would move and most dentists just perceive that the risk is not worth the prices they charge to get the dental care done. So the typical response that you get is 'I'm not equipped to work with a patient that has special needs.'"

Finding a dentist who accepted their insurance compounded the families' struggles in securing a regular provider. A majority of the families interviewed had Medi-Cal dental insurance. Finding providers that were willing to see children with SHCN, and accepted publicly funded insurance was a barrier.

"And since we moved, I found two different dental offices. But just going there twice, they don't want to provide dental care for [my son] anymore. Yeah, it's being hectic. My other kids are receiving dental care, but [my son], I can't find any office that will accept the dental insurance and assist kids with special needs. So it's difficult."

For those that eventually found an accepting provider, wait times were a major barrier to actually getting them in the door.

"And we found out the waiting time on that was three or four years ... So we kind of just knew he had six cavities and hoped and prayed that they weren't causing any pain."

Provider rapport – dismissive:

Parents noted that they put a high value on the dental provider's interaction with their child during the visit. A provider that did not have good chairside manner or did not treat the family with respect, especially one who was dismissive, could effectively discourage families from seeking regular dental care for their child due to their negative experiences.

“But I just felt like when they [a dentist] see a special needs child or you tell them, “Oh, my son has autism,” I just felt like they didn't even try. The doctor we had gone to initially wouldn't even look at him, wouldn't even try. He walked in the room and he saw that my son was upset and he was like, “Well, we can't do anything. He needs to be sedated. I won't even attempt. I'm not going to do anything. We need to send him.”. ... It was almost like, ‘This is what's going to be easier for me [referring patient out], so that's what we're doing.’ “

Another aspect of provider rapport that parents mentioned was how the dentist and staff interacted with their child, particularly if they were approaching adulthood. Parents wanted their children to be addressed at an age-appropriate level and be shown the same level of respect that any other patient of the same age would receive.

“I just feel like, with a lot of special needs, I think that they get looked over quite a bit. I think a lot of people, it's unfamiliar to them. Nobody wants to be talked down to. It's very dehumanizing. So even if they or anybody takes their time to just try... Don't talk to them like they're a baby. Talk to them like you normally would.”

Proximity of provider/transportation:

Another major barrier that appeared during interviews was the proximity of an available provider to the family home, and the transportation available to the families to get them to the dental office. Many families noted that they had to travel a very far distance to find a provider that would see their child.

“So we live in the [rural California region]. So from [rural California] to San Francisco, if there was no traffic or accidents, I feel like it would take maybe about, I'll say three-and-a-half, maybe four hours to get there. But if there is traffic, accident, or fires along the freeway, then I feel like that could take up to six hours to get there.”

The reality that there isn't an office that's geographically accessible for a lot of these families means that often times their children with SHCN aren't seen regularly, delay their visits, or aren't seen at all.

"If I do have to make an appointment, it has to be two hours [away] and I have to drive to San Francisco. So I'm kind of hoping like, "Oh, okay. Maybe the swelling or the redness will go down." Instead of calling the dentist right away. I feel like if it was closer, I might be more prompt to get an appointment for him to just be checked out. But because it's that drive, I hold off on taking him."

An added dimension to the distance that some families must travel for a dental visit is the cost and logistics that are associated with the transportation of getting there.

"Unless I have that money for gas, I can't guarantee that I can get there because... I might have to cancel it because it is a couple of hundred dollars, maybe \$300 alone just going down there because you have to pay parking, you have to pay all that, and that's not cheap there."

Enablers:

Effective behavior management:

When working with children with SHCN, a dental provider often needs to utilize behavior management strategies to deliver care. The parents of these children understand that not every appointment will go according to plan, but parents stated that there are ways that dental providers can support their children. One aspect of effective behavior management that parents mentioned was the use of distractions during the exam, and being flexible with how appointments are conducted.

"We usually use sensory lights to help him calm down, distraction, and I believe he just got his teeth cleaned. He did great. As long as he has all those distractions and they're helping him calm down, he seems okay."

Another tool that parents said was helpful in getting their child into regular dental care was the use of visual preparation ahead of the visit.

"And so I also have been doing a lot of visual schedules for him, just getting him prepared ... I would think that it will be helpful that clinics have those visuals for kiddos as well. It just helps them transition better to things coming up, especially kids that have delays and need a little bit more help in understanding."

Continuity of provider/care:

The next enabler that parents placed a high priority on was establishing an ongoing relationship with a provider and their child. Many parents felt that some consistency in the dental appointment experience would lead to more successful visits.

“I think the main thing is just having the same staff work with him every time, because I think that they know what to expect and I don’t have to take the first 30 minutes of the visit to explain his self-injurious behaviors that could happen ... I feel like just having the dental staff be able to get to know us ahead of time, has been helpful”

Continuity of care also means that their child gets the chance to desensitize to the dental office, with the hope that they become more comfortable as they get more exposure to the office.

“But what we’ve done is we’ve come enough and had the same dentist over and over, calm demeanor and desensitized him. So now he’ll go in without crying and he’ll sit in the chair. He doesn’t like the glasses or the bib they put on, but they always turn on his favorite show on the TV and they angle it so he can see. They go slow and tell them everything they’re doing. And now he will hold his mouth open and let them check or brush or floss.”

Provider rapport - positive attitude:

The attitude of the dental provider, and their interaction with the families is an enabler to children with SHCN maintaining a dental home. Parents that had a provider that supported their child in having a positive experience stated that they were more encouraged to return for regular dental visits. Many parents appreciated the providers that tried to make an otherwise potentially stressful appointment as fun and engaging as possible. The dental visit then became something that their child looked forward to.

“It was like, ‘I’m going to hang out with my friend [the hygienist] and [the dentist]. They have a big trunk with toys and we hang out and we listen to Wiggles music for about 30 minutes, and then we open my mouth and then we sing some more. Then we open my mouth again, and then we brush.’ I mean, toward the end, they could even use the ... cleaning machines and flossing”

Other parents simply appreciated the providers that took their time to talk to their child and to their families. Dentists that showed empathy and understanding of a stressful situation were especially important to enabling these families to return for dental care.

“I called into [a dental office] and they turn away most people. They don’t have a big clinic, but they approved him. And I went in there and you always know when you’re working with someone who actually cares ... the way he treated us, that was incredible. We had a wonderful experience.”

Referral to an accepting provider:

For the families that had difficulties finding a provider that would see their child with SHCN, a referral to an office that took their insurance, and was willing to see their child was often the key to establishing regular dental care. Navigating the healthcare system is stressful for these families, and many did not know where to look when it came to finding a dentist for their child. Many of the parents that were able to find a dental home for their child stated that they were referred from an outside source. Most of those referrals came from within their healthcare system.

“[I was referred] from his pediatrician. I was having a hard time finding a dentist, because most of the dental offices doesn’t do O.R. and my son has a heart problem. So I asked his pediatrician if they can refer me to a dental specialist and they’re the ones who referred me to UCSF.”

Many parents were able to find a dental home for their child thanks to the parent network of other children with SHCN.

“I was trying to find on the internet, Google, but nobody described anything about special needs appointments. The only thing that worked was by word of mouth with parents. I think it was at a support for families event where we met together and we discussed, “Oh, we have the same problem of where to go.” And one of the parents mentioned, “Okay, you can try UCSF because they know what to do with special needs.”

Overall, the fifty interviews with caregivers of patients with SHCN resulted in robust and diverse insight into the many barriers and potential enablers to children with SHCN obtaining routine dental care.

Discussion:

When comparing the findings of this study to a systematic review published in 2020 titled *Barriers in Access to Dental Services Hindering the Treatment of People with Disabilities*, there were some similarities in identified barriers. Both this study and the 2020 study highlighted the provider’s

ability and willingness to treat a patient with SHCN as a key barrier to dental care for this population. Physical barriers were also noted in both papers, although the 2020 study focused more on the lack of facilities that were accessible to patients with physical disabilities, while this study found that distance to an accepting office was a key physical barrier. The major difference between the two studies was that this study identified enablers and facilitators to accessing dental care, while the 2020 study noted that none of the selected studies discussed facilitators of access to oral health services for people with SHCN. The facilitators identified in this study can inform future interventions to increase access to dental care for those with SHCN.

An important finding in this study was that on average, children with SHCN obtain routine preventive dental care less frequently than the recommended periodicity. According to the AAPD, periodicity of dental visits for children at high risk for caries with SHCN should be every 3 months. However, this study found that on average, dental visits occurred every 9 months for the study population. Prior studies have shown that children who receive dental care under GA are likely to develop future caries, and that more frequent recall visits are associated with less likely disease occurrence.^{xii}, ^{xiii} Once a child has completed dental care with GA, they have had all of their caries treated and are essentially “caries-free”. It is then absolutely imperative to place an emphasis on future disease prevention, home oral hygiene, diet and routine dental care to prevent recurrent or new disease in these high caries risk children.

Another key finding from this study was the fact that on average, families drove 65.8 miles one direction to obtain dental care for their child at UCSF. This not only speaks to the lack of providers in non-urban areas, but also to the lack of providers that are willing and able to treat children with SHCN. This finding is supported by other studies that have identified that the healthcare systems capacity to provide dental care to those with SHCN is very low.^{xiv} Future initiatives to increase providers, especially in non-urban communities, who accept, are trained, and felt comfortable seeing children, adolescents and adults with SHCN could alleviate some of the barriers these families face.

Lastly, this study found that 66.4% of the study population returned to UCSF for dental care of any kind after their GA appointment. However, this does not necessarily indicate that other families did not have a dental home for their child with SHCN. For the one-third of patients who never returned to UCSF for dental visits following dental care with GA, these families may have found a new dental home, moved out of the area, or may have sought dental care in some other method or location. While the qualitative interviews showed that most families had a difficult time finding a local dental provider, a weakness of this study was the lack of follow up with all patients of the study population.

A strength of this study is the diversity of the SHCN population that was interviewed. Children with different SHCN may have specific challenges when accessing dental care, and this study made a conscious effort to include many different SHCN diagnoses. A large qualitative sample size was used in this study due to the homogeneity of the study population. Since this study was conducted on a population that is located in northern California, and children that have had dental treatment under GA at UCSF, these results may not be generalizable to all children with SHCN.

Conclusion:

Children with SHCN face many barriers when trying to access routine dental care. Children with SHCN do not always return for routine dental care, follow up and prevention following dental treatment it GA. Child stress/anxiety, finding an accepting provider, dismissive providers, and the proximity of provider contribute to challenges in children with SHCN obtaining dental care. Effective behavior management, continuity of provider/care, positive provider attitude, and referrals to an accepting provider can help mitigate the lack of access to regular dental care that many of these families face.

Appendix

Table 1 – Chart review and interview demographics

	Chart Review Demographics (n=, percent)	Interview Demographics (n=, percent)
Demographics		
Age at GA	8.6 (SD 6.6)	8.5 (SD 4.3)
Age at Data Collection for Study	14.5 (SD 6.7)	14.2 (SD 4.4)
Primary Language Spoken at Home		
English	384 (77.11%)	42 (84%)
Spanish	70 (14.06%)	6 (12%)
Chinese (Cantonese and/or Mandarin)	7 (1.41%)	2 (4%)
Other	7 (1.41%)	-
Unknown	30 (6.02%)	-
SHCN Primary Indication for Dental Treatment under GA		
Autism/Neurodevelopmental Disorder	142 (28.51%)	15 (30%)
Genetic/Chromosomal Abnormality	98 (19.68%)	14 (28%)
Developmental Delay	73 (14.66%)	7 (14%)
Cardiac	63 (12.65%)	5 (10%)
Cerebral Palsy/Seizure Disorder	62 (12.45%)	7 (14%)
Cancer	23 (4.26%)	-
Bleeding Disorder	10 (2.01%)	-
Skeletal/Connective Tissue	9 (1.81%)	1 (2%)
Non-Syndromic Craniofacial Anomaly	8 (1.61%)	-
Other	8 (1.61%)	1 (2%)
Dental Anomaly (AI/DI)	2 (0.40%)	-

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