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Strategies for Success: A Qualitative Study of Caregiver and Dentist Approaches to Improving Oral Care for Children with Autism Spectrum Disorder

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Abstract

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Purpose: Oral health is important to physical and psychological health. Individuals with autism spectrum disorder (ASD) experience significant oral care challenges, but little research exists examining efficacious interventions to improve care. This study qualitatively explored parent-and dentist-reports of successful strategies implemented during dental care with children with ASD.

Methods: Focus groups were conducted with parents of children with ASD (n=2 groups) and dentists treating children with ASD (n=2 groups). Focus group transcripts were transcribed verbatim and analyzed using a thematic analysis approach.

Results: Three key themes were identified from the parent focus groups: (1) *What makes a good dentist*, (2) *Flexibility and techniques: strategies used by the dentist*, and (3) *Preparation: strategies for parents and caregivers of children with ASD*. Four themes emerged from the dentist groups: (1) *Parents know best*, (2) *Practice*, (3) *Flexibility*, and (4) *Network of colleagues*. Areas of overlap between the parents and dental providers included the importance of preparation, the necessity of flexibility and creativity, and the value of collaboration.

Conclusions: Findings provide insight into techniques perceived by parents and dental providers to facilitate successful dental encounters for children with ASD.

Keywords

Autism Spectrum Disorder; Oral health; Dental care; Occupational therapy; qualitative research

Children with autism spectrum disorder (ASD) experience greater challenges with oral care in the home and dental office compared to their typically developing peers.[1] Many barriers to treatment have been identified for this population, including: inadequate numbers of dentists trained and willing to work with children with ASD and other special health care needs,[2-5] financial issues for both the providers and parents,[3,6-8] and possible legal issues regarding restraint.[9, 10] Additionally, recent research suggests that personal characteristics inherent to the disorder (e.g., deficits in communication, insistence on sameness, over-responsiveness to sensory stimuli)[11] and environmental factors of the dental environment can also act as barriers to proper oral care for children with ASD.[12-15]

Despite the large number of barriers to treatment, few high-quality interventions have been designed and implemented to improve care for this population. Of the six intervention studies identified in a systematic review,[16] only two were of adequate or strong methodological quality. These two studies focused on improving oral care by decreasing stress and uncooperative behaviors at the dentist by adapting the sensory features of the dental environment[12] or by utilizing electronic screen media as a distraction during dental care.[17] The remaining articles examined home-based training programs and visual supports to improve care in the home and dental office. Because the dearth of successful, high quality intervention studies, an examination of the successful strategies currently utilized by dental professionals and parents to facilitate care for these children is needed in order to inform future intervention research.

As the prevalence of ASD increases, with current statistics in the United States reported to be 1 in 59 children,[18] dentists are increasingly likely to encounter children with ASD in their practice and therefore the need to address known barriers becomes of even greater import.

The purpose of this study was to gather information on the current strategies implemented by dental professionals and parents of children with ASD to facilitate successful oral care encounters. Using qualitative data obtained from focus groups of parents of children with ASD and dental professionals treating children with ASD, we examined data to provide insight into how to create the optimal dental experience for children with ASD.

Methods

Study sample.

Given the demands of parents of children with ASD and the limited number of providers with extensive experience with this population, our goal was to recruit participants to conduct at least one focus group with each group. Due to the recruitment efforts described below, we were able to conduct two focus groups with each population. Additionally, focus groups were purposely kept small (4-5 participants each) to allow all participants sufficient time to share their stories and experiences.

Consecutive sampling of parents living in the Southern California area that responded to brochures and flyers posted in local school districts and two large urban hospitals took place. Parents who met inclusion criteria had at least one child with ASD between the ages of 2 and 18 years at the time of recruitment and were fluent in English. Target recruitment was 10 caregivers total. However, as it is common for participants to miss focus groups, 13 parents were scheduled to participate in one of two focus groups that took place between April of 2011 and 2013; of those scheduled and confirmed, 9 attended and all were consented. See Table 1 for caregiver and child information. Additional information about these focus groups was presented elsewhere; see Stein Duker et al.[8]

Dentists with a minimum of one year experience working with children with special health care needs who had treated at least eight children with ASD in the previous year were recruited to participate in the dental professional focus groups. A purposive sampling strategy focused on recruiting providers with experience treating children with ASD, identified through snowball sampling strategies starting with expert providers known to the research team. A total of 11 dentists accepted and were scheduled to participate in one of two focus groups that took place between April 2012 and June 2013; 7 dental professionals participated, see Table 1.

Data collection.

Semi-structured interview questions were developed to elicit detailed stories about oral care-related challenges experienced by children with ASD and the strategies employed to address them. Questions were crafted by the authors, reviewed and edited by an expert pediatric dentist, and then reviewed and edited by an expert in qualitative research. Questions for both groups included prompts about strategies used to make professional and home dental care successful, who implemented these strategies (e.g., parent, dental professional, or child), whether or not these strategies were effective, and opinions as to why they did or did not work.

In each group, the moderator gave a brief presentation of the purpose of the focus group and then began with the first semi-structured question. Although a question list was used to guide the discussion, the moderator was instructed to further probe strategies used to address children's oral care challenges based on participants' verbal and nonverbal responses as well as any other salient experiences that participants wished to discuss. Each group lasted approximately 2.5-3 hours long, was tape recorded, and was transcribed verbatim.

Data analysis.

Thematic analysis following a grounded theory approach[19] was used in order to describe parent and dentist implemented strategies to address the oral care challenges of children with ASD. For each study group (parents and dental professionals), the research team independently read and coded one of two transcripts from each group before meeting to create a list of codes and sub-codes that could be applied to all transcripts. These codes were developed inductively from the data but informed by sensitizing concepts gleaned from the literature. Then, using the agreed upon list of codes, team members went back to the original transcript to independently code before meeting to compare coded materials. This same process was then used on the transcript from the second focus group. Inter-rater agreement for parent focus group codes was 98%, and 97% for dental professional codes.

Discrepancies in coding were resolved through discussion until a consensus was reached. This process of co-coding constitutes a strategy of rigor in qualitative research.[20] Other strategies that were utilized to support the credibility and trustworthiness of these findings included peer researcher debriefing, negative case analysis, consensus-driven thematic development, and maintaining an audit trail for analytic decisions.[20]

This study was approved for human subjects by the Institutional Review Board of the University of Southern California Health Sciences (HS-09-00691 and HS-11-00733). All participants provided written informed consent.

Results

Three themes regarding strategies to improve oral care for children with ASD emerged from parents of children with ASD, including: What Makes a Good Dentist, Strategies for the Dental Professional, and Strategies for the Child and Caregiver. Four themes were identified from the dental professional focus groups: Parents Know Best, Practice, Flexibility, and Network of Colleagues.

Parent Results

What Makes a Good Dentist.—Although participants were not explicitly asked about what made a "good" dentist, this topic quickly emerged as an important theme. Parents reported that a good dentist was integral to oral care success for their children, exemplified by dentists' knowledge, understanding and experience. All parents emphasized that calm, understanding dentists who were supportive, regardless of the behavior of the child, were essential. Multiple parents recalled dental experiences with professionals that they felt had "no awareness of how to handle a special needs kid". These negative encounters were juxtaposed with positive ones where

> All the staff…are sensitive to working with special needs…they all kinda talk through what they're doing and they are all really open to working with him… nobody is cranky and they all just seem to *get it*.

When describing visits, multiple parents even remarked that their dental professional's knowledge was supplemented by having a family member or relative with an ASD diagnosis; "…and he [the dentist] understands kids, and his hygienist has an autistic son, so, I don't think you could ask for much more." Experience and knowledge, whether it was obtained via formal training or just "doing this for many many years" was touted as a positive attribute for a dentist by all parents.

Parents also agreed that positive reinforcement and tone of voice were essential components of a successful dental cleaning. One parent explained,

> …a lot of positive reinforcement is helpful to my son, but I'm also going to throw in that it is helpful to me. It's important for me to see that the dentist is sensitive to my son and the way that it is and it just it doesn't faze her [the dentist] the same way it would someone else. Like he [my son] could be like completely melting [down] right there having like wanting to get out and you know it's embarrassing or like it gets very tense and to see her [the dentist] just be understanding and not change and just keep at it and keep her positive reinforcement…it's horrible to be going through all that and then on top of it to have a provider fall into that and get mad or get upset and to me that is very helpful, the sensitivity part.

The use of "nourishing types of tones" during communication, patience when visits didn't go as expected, and flexibility were also reported as helpful in supporting positive visits. Flexibility when trying new strategies to find what is most successful was described as essential; "trial and error" was mentioned repeatedly throughout both focus groups. Trial and error to identify successful strategies could be a lengthy process, as described by one parent explaining that "the challenge was finding what would work, and we did all those [other] things" prior to finding what was best.

Flexibility and Techniques: Strategies Used by the Dentist.—Parents offered a number of strategies that were utilized by the dental professional in order to facilitate successful dental visits with their children. These strategies included: (1) strategic scheduling of visits, (2) coordination with other professionals, and (3) providing individualized care.

Strategic scheduling of visits.—All parents emphasized the importance of scheduling; this included planning dental visits to ensure short wait times as well as considering the time of day of the appointment. To exemplify the importance of minimal wait times, one mother explained

> …maybe that's something that the dentist should know; that with these kids when your appointment is for 10 it needs to be at 10 and he needs to see the dentist at 10… 'Cause the longer they wait, the worse it gets…it's that 'okay, we're here!', now let's do it and be done…that'd be good for them [dentists] to know.

Another mother agreed, indicating that it was not just a short wait time in the waiting room, but also in the clinic itself, "…when they took [son] into the room it was pretty quick so I was happy about that; then I'm like 'Oh no, now we're going to wait here for the dentist,' so my anxiety was starting to build…". Multiple parents stated that they preferred the last appointment of the day since there were fewer people in the waiting room and often a shorter wait. However, parents also mentioned the individualized nature of this strategy, noting that some children did best first thing in the morning compared to later in the afternoon.

Coordination with other health professionals.—Half the parents noted that they had previously solicited help from other non-dental health professionals, primarily behavioral therapists. This help took place in both the home and dental office environments. For example, one parent described how much it helped when "…we integrated his dental visits with his ABA [applied behavior analysis] so we actually brought his ABA therapist with us to dental appoints for probably two years". Other parents described successful experiences using therapist support in the home to help prepare for visits. One father recalled how helpful it had been to work together to make social stories, with each story about a different topic "…a story about going to the doctor, or cutting your hair, or whatever…", remarking that after utilizing these social stories for a while they were able to graduate to only using verbal prompts to prepare him for dental visits.

Providing individualized care.—Parents agreed on the utility of a variety of strategies and adaptations employed by dental professionals to improve the dental experience for their child with ASD. However, parents were also quick to point out that no strategy was one-size-fits-all and the importance of trial and error in identifying what did work for each individual child, emphasizing that "finding the right method…was the biggest challenge" and that this process could require multiple years to find or might never quite materialize, even with trying multiple strategies along the way.

Practice visits to the dentist were described as helpful to familiarize children with the dental environment and dental cleaning activities. One mother described that a dentist "…said we are not gonna do anything that upsets [her son], we just want to set the tone for the dentist as being a good thing…that was really wise", explaining that her son's first visit would only include sitting in the chair and practicing, following a previous bad experience with another dentist. Second, parents noted the success of *taking breaks* throughout the cleaning, with one parent explaining that "…we take a minute, two minute break…we let him get up, take a walk, just a breather." For some children, breaks were implemented at regular intervals, while for others they were utilized on an "as needed basis". Parents noted that it was often still difficult to get the child back into the dental chair to finish the dental cleaning after the break, but that the breaks made the cleaning more manageable without multiple tantrums. Third, *quick cleanings* were described as ideal, with multiple parents describing that their child has "…a window of time…[and] once time's up then that's when he starts to fight you" so the dentist had to be "nimble" and "speedy"" A fourth successful strategy endorsed by parents was the importance of the dentist using *child-friendly communication* strategies to describe oral care procedures. This was exemplified by the search for and destruction of

"sugar bugs" by the dentist and was also utilized successfully in the home environment for toothbrushing. Parents remarked that the children were either horrified by the idea of bugs in their mouth or enjoyed the game-like aspect of the dentist searching for sugar bugs in order to destroy them. Fifth, parents agreed that ensuring the child *never saw* the "scary" side of any of the tools was very helpful in creating a successful dental encounter. For example, one parent recalled how the dentist

> …asked the nurse for the scraper, but my son never saw the scraper, and he [the dentist] went back to my son's teeth and started counting and using the scraper…so he [my son] never actually felt it, which I though was so impressive…I was like 'Oh, that's so good, that's so smart'. So I think he was very aware of the anxiety that the kids have.

Sixth, the use of *sensory strategies* was endorsed by the majority of the parents, describing the use of sunglasses or baseball hats to help with bright lights, headphones or knit hats to help with loud noises, and "pressure on his shoulders, on his arms, I hug him tight" to provide deep calming touch sensations during dental cleanings. However, the use of sensory strategies was not a panacea, as one mother described her son's negative responses to bright lights, but also commented that he had difficulty tolerating anything on his face or head (e.g., hat, sunglasses) to block those lights. Seventh, the use of a "*treasure chest*" by the dentist at the end of the cleaning was favored by parents. These treasure chests went hand-in-hand with the positive reinforcement provided by the dentist and contained small prizes that the child could choose from at the end of the dental cleaning. Parents noted that this was a valuable reward for good behavior throughout the cleaning, but that it was also important to reward "trying hard", even following a challenging and less successful appointment. The last strategy focused on the importance of the waiting room and dental clinic *environments*. Some parents discussed the benefits of pediatric dentist offices that were designed to be very child-friendly and "very inviting", incorporating "video games in the lobby" and "cartoons above every [dental] station, legos in the waiting room". Other parents focused on environmental adaptations used to promote relaxation, with multiple parents endorsing the benefits of fish tanks or water fountains. One mother stated that her dentist had

> …those little water things like little fountains…so he'll sit there and just look at that or sometimes they'll have fish tanks or he likes looking at the little water thing and I think it relaxes him a little bit before he goes inside."

Another mother described "a little cave" that her son could enter in order to have some quiet time prior to his dental visit. Although creating the optimal dental environment required a delicate balance between designing an exciting child-friendly space and ensuring that children with sensory sensitivities didn't become over-stimulated, all parents endorsed the importance of the environment.

Preparation: Strategies for Parents and Caregivers of Children with ASD.— Parents also offered a number of preparation-based strategies to be utilized by themselves and other caregivers to increase the chance of a successful dental encounter. First, parents explained the importance of *warning* the child that a dentist appointment is coming soon. As one mother explained, "…preparing them because that is the one thing they cannot deal with

is the change of routine, so always pre-notify them, I think it is very important." Some parents describing preparing the child the whole week while others only told the child about the dental visit the day before; this amount of time required the parent's knowledge of "how much time he needs to process it [the upcoming visit] without freaking out."

Second, the majority of parents described *practicing* what would happen at the visit with their child. For example, one detailed how she

> …practiced opening my son's mouth and brushing and said "This is what the dentist is going to do, he's going to look at your teeth, he's going to count your teeth, and whatever", and so when he [the dentist] did look at his mouth my son did open his mouth, and when he [the dentist] was counting, he [my son] was used to counting.

Parents stated that they did this type of practice multiple times daily for a week or sometimes longer leading up to visits, describing that "He might be walking by and [I'm] like 'let me see you open aaaah, say aaaah, open your mouth.' So all these little things leading up to [the visit] I think…[make] it a little bit easier for the child." Parents also recounted the use of watching online videos or pictures of the office to prepare their child. One mother described that her ….son likes YouTube, and so I went on YouTube and… showed him a couple videos…like, this is what we are gonna do, we're going to the dentist. Another parent described that "the dentist has pictures of his office on his website, so I showed him [her son] where we were going, and that kinda thing." Parents also utilized visual schedules to practice at home, with one describing that "we have a list on the wall, we tell him we're going to the dentist and we're going to see this; I don't know who's going to be there…so that nothing that happens at the dental office is a surprise."

Last, parents commented on how planning for the visit and *bringing items* to the office often helped to facilitate positive experiences. These items often included sunglasses, hats, headphones, music, etc. to try to decrease the intensity of sensory stimuli in the office, a fidget toy, or even a comfort item. Parents described bringing a "bag of tricks – his favorite toys to try to use and have on hand…they'll be helpful at that time [during the visit]." Multiple parents also eloquently explained the trial and error process and how "you just gotta find what motivates [your kid]. Their 'currency…'", once again exemplifying the importance of individualized and tailored strategies to work with this population.

Dentist Results

Parents Know Best.—Participating dentists valued parental input during appointments in order to get information about the specific needs of patients. All dentists noted the importance of including parents in the care process, describing how creating a relationship based on open communication was key to establishing trust with parents. One dentist described how communication was essential to obtain parental buy-in of oral care activities, explaining that

> If you tell the parents the procedure they have to go through to fix a cavity if [the child is] uncooperative, you have to put them to sleep, it's a hospital visit, there are

> risks involved and that it is completely preventable…they realize how important it [oral care in the home and dental office] is."

Once in agreement with the dentist's treatment plan, parents were considered primary informants about their children, helping the dentist to achieve better outcomes during visits. One dentist, after encountering challenges treating children with ASD, noted that he could "utilize some of the same strategies the family uses at home" to support successful visits. For example, one dentist recounted one of his most memorable success stories, describing how, based on advice from the family, he was finally able to get a girl with ASD into the dental chair after having to treat her on the floor for years.

> Mom says, she [the daughter] has this little animal. And if she has this little creature she'll about do anything for me at home. And I said bring [the animal] around…we'll see what happens. So she brings it in the next time. Low and behold she's sitting in the dental chair. And this little - not so little - iguana is sitting right on her chest…For years we would do her cleaning on the floor, we would, you know, just about stand on our head to do everything. And it takes a while sometimes to get smart [and] actually ask the mother…how do you get her to do anything at home?

Utilization of parent knowledge also extended to determining types of positive reinforcement and external motivators for each individual child. For example, one dentist noted "some parents bring in gifts that I keep for that particular patient, or a certain game that they will play." Another dentist shared that parents might "bring in something from home…whether it be a stuffed animal or the promise of their favorite treat…if it works, it works." As summed up aptly by one practitioner, "…nobody knows them better than their parents".

Practice.—This theme referred to strategies employed at home and at the dental office to prepare children for future appointments by increasing experience with various aspects of dental visits. All providers mentioned the importance of desensitization as a strategy for diminishing aversion to the dental clinic. The process of familiarizing children with the dental environment often began before officially scheduled visits, with dentists encouraging children to come by the office to sit in the dental chair and get used to the feel of it. One dentist explained that

> …it takes multiple repeated, repeated, repeated, repeated experiences. Which is the desensitization and all the things that we do…We have what's called an open door policy in the office. As soon as we meet the mom and the child and all that, if they're running through going somewhere, going shopping or something…at any time of the day and whatever day it is, drop in, come in, get a hug and a toy and you're out the door. And that's sort of the desensitization.

Similarly, another provider echoed, "…I may just have them come and sit in the office and just get used to the office, and then come and sit in the chair. I don't even go in the room. Just let them get used to the chair…".

Alongside multiple preparatory office visits, providing the family with tools and resources to practice at home also was believed to help. One dentist stated that he commonly asked parents

> …to get any book and every book…on dentistry, and get them to talk with [their child] about it. I say lay them back, if you have a recliner, lay them back…look in their mouth…brush their teeth while they're laying back and say this is what the [dentist] will do…

Dentists also suggested including the child's therapist to introduce dental concepts in the home prior to dental visits. For example, one dentist explained that "…when we get to things like x-rays and things like that, when they've got to have stuff in their mouth, I have the therapist take some x-rays home with them, get them used to *them* [the therapist] putting it in their [the child's] mouths." Providing the family with a written step-by-step checklist to review at home and then follow during the visit was also a popular strategy with our participants; the concrete nature of tasks to complete and "check off" were specifically noted as helpful for some of the children with ASD.

Dentists also emphasized the length of time the desensitization process could require, as familiarity and comfort with the dental clinic and staff can take considerable time to achieve. One dentist explained that he arranged "to see this child every 3-6 months [to] work them towards sitting in that chair just like everybody else…whether it happens this year or next year or whatever, that's our goal, that's what we want." Another dentist recalled

> …one patient that I saw at [clinic name] at 13 years old under general anesthesia. After, his parents brought him to my private practice and I said I don't need to put him under general anesthesia, I can just talk with him. And I worked him through, and now at 25 years old, I can do a crown on him without any general anesthesia and no problem at all.

While the practice of multiple visits to increase exposure may be effective to facilitate successful care, from a fiscal perspective it was reported to present challenges. One dentist explained the difficulty she experienced between wanting to offer her time to families and needing to break even financially.

> Yeah, there's no billing. On a very rare occasion, if we've done it like 15 times, I'd ask the parent, you know come on, I've done this 15 times, can you pay for like one office visit? It's like one office visit over 15 visits [is paid], maybe 2 office visits over 15 times. I mean we - normally we're not getting paid.

Flexibility.—Dentists repeatedly mentioned being flexible to accommodate the needs of children with ASD, including changing their traditional treatment methods, employing new techniques, and approaching all situations with an open mind. Multiple practitioners in both focus groups explained that there was no "one size fits all" approach to working with children with ASD; each child was seen as unique with different strengths and challenges and thereby required an individualized approach. In a moment of unity during one focus group, the dentists came together to echo this sentiment. The first dentist commented that

> you sort have to be flexible…in our little clinic in xxx there's a couple of benches. If the child will let you sit next to them on the bench and sort of open their mouth and let you look, they don't want to lay in the chair, that's fine. It's just you do it, or if you have to go to the floor, you go to the floor.

The next dentist replied that "if you have to go to the parking lot…" you do so in order to complete the treatment, while the third remarked "…or down the street, I've done 'em in the middle of the street, yeah. I think what's different from what I've noticed of people like ourselves and other dentists, is that we do, like you said, think outside the box. I think it's, for me the goal is to care for this child at whatever cost." The next dentist replied that, "You can't be rigid in your mindset of 'I must do dentistry this way,' because if you are, you're out of the water…Every child is different. You have to treat every child different, you have to think outside of the box for every single one of those children." Lastly, as summed up by one of the dental practitioners, "it is just taking the time and doing whatever you have to do to modify your treatment".

Practitioners emphasized the need to have an open mind and expansive perspective when working with children with ASD. Some dentists reframed experiences to recognize minute actions as improvements to accomplishing the whole, as illustrated by one dentist when he noted that just "getting him just in the chair can be a tremendous success". Another dentist described that she believes that "The child just has a disability but he's not stupid, he's smart. You're just not giving him a chance by making all these preconceived notions on him."

Network of Colleagues.—Dentists also spoke of seeking the advice of other healthcare providers regarding strategies for working with the ASD population. This network of colleagues included other dental professionals as well as healthcare providers from outside of dentistry, such as occupational therapists, physical therapists, and behavioral therapists. All participants agreed on the importance "for the doctor [dentist] to be mentored" in order to improve new clinician skills, answer questions, and improve practice with children with ASD. Several dentists also expressed the desire to establish a mentorship system to educate future generations of dental practitioners working with special needs patients. In this way, new dentists could learn from the experiences of seasoned specialists noted for their work.

Participants involved in supervising dental residencies reported that dental residents often echoed these sentiments, asking for mentorship; this was well-received by their attending supervisors, although formal mentoring networks were not always readily available,

> I think that if somebody expressed an interest and they've [not done] this before, and they say, 'You know I'd like to do that,' they need to get linked with somebody in their community that's doing it…If you had someone come in and shadow you in your office and come in and work…I think it would be nice to have a mentorship program in our community.

Several dentists also expressed the importance of utilizing knowledge from other professions, such as occupational therapy, physical therapy, and behavioral therapy, to

facilitate dental visits and provide education about ASD. One provider discussed how he valued outside opinions from other professions, explaining how

> We learn so much from our medical colleagues, whether it's OT [occupational therapy], PT [physical therapy], or any of the other pediatricians…in grand rounds, I want to see who's talking. Well if there's an OT or PT person talking and they're going to talk about children that have autism, I'm going to be there. I want to hear their perspective, their tricks, what they're going to do, and I'm not sure that we can always turn to our dental colleagues for that information.

Likewise, if another health care provider was treating the child, dentists remarked how they should value their opinions and seek their counsel and be open to anyone, "…a teacher, a therapist, whoever is working with the child, invite them to come because we'd love to have them join in and help us." Another dentist agreed, stating that "A kid on the ASD spectrum is going to have behavioral therapists and if they are with the parents, it's very helpful. If there is an OT there, listen to them."

Overlapping Themes

In examining the qualitative results from both respondent groups, it became apparent that there were several overlapping key themes. These three themes included: preparation, flexibility and/or the use of creative strategies, and collaboration with other professionals. See Table 2.

Discussion

These findings are among the first from qualitative research to explore potential strategies to address the oft-reported challenges and stressors encountered by children with ASD and their families during visits to the dentist. Due to the individualized nature of ASD, it is difficult to discern what comprises best practices for this population. However, in this study, the confluence of both parent- and dentist-reports aim to provide insight into techniques perceived by both parents and dentists as effective for supporting successful dental encounters for children with ASD, with the primary strategies suggested by both participant groups.

Parents and dental professionals repeatedly discussed the importance of preparation both for the home and dental environments. In the home, preparation centered on practicing activities to take place during dental visits by watching videos, reading books, and using visual schedules or step-by-step lists of oral care activities. In the dental office, preparation focused on multiple desensitization appointments where the child could visit the office prior to the cleaning. The utilization of these types of preparation activities have previously been reported, with 71% of dentist members of the Special Care Dentistry Association who treated patients with ASD offering familiarization visits[21] and parents of children with ASD also endorsing the importance of adequate preparation such as using social stories.[22, 23] Despite the recommendation to include preparatory strategies such as these by the National Institute of Dental and Craniofacial Research[14] and the Autism Speaks dental toolkit,[24] little research has been conducted harnessing these techniques to prepare children with ASD for oral care in the dental office. Three intervention studies have attempted to improve dental

visits using preparation. Two of the interventions utilized a visual training protocol for children with ASD, with results suggesting preliminary support for increased cooperation with some components of routine dental cleanings[25] and a 93% acceptance for both oral examination and prophylaxis following the intervention.[26] In the third study, watching a video of a typical child undergo a dental cleaning prior to the dental visit did not significantly change anxiety or uncooperative behavior; however, there was a significant decrease in anxiety and uncooperative behavior when watching the video in the home was combined with watching a movie on video goggles during the dental visit.[17] However, upon review, the methodological quality of these studies were found to be weak, weak, and adequate, respectively.[16] Recently, a retrospective review of behavioral data of children with ASD found that almost 90% of children who participated in a dental desensitization program (including individualized care plan, social story, previsit preparation in the home) with five or fewer clinical desensitization visits were able to tolerate a seated dental examination with an intraoral mirror.[27]

Despite the endorsement of preparation activities by dentists and parents, both groups also emphasized that even with well thought out and structured preparatory activities cooperation for dental cleanings was not always possible. This “sometimes but not always” success exemplified the second major overlap between dentists and parent strategies for success – flexibility. In our data, flexibility focused on providing individually tailored care by accommodating a child’s specific interests and/or challenges as well as recognizing that successful strategies were not “one size fits all” – a phrase repeated in multiple parent and practitioner focus groups as well as in previous research.[22] Flexibility and creativity are essential in the dental office, as simultaneous use of multiple accommodations may benefit children with special health care needs, especially those with ASD.[21,28,29] In fact, one study surveying Special Care Dentistry Association Members found that respondents utilized an average of 6.34 accommodations to address difficulties with communication, routine, and social interactions when providing dental care for children with ASD.[21]

Lastly, both parents and dentists mentioned the importance of collaborating with other professionals to facilitate positive dental encounters for children with ASD. Parents focused on the utilization of related services to address oral care challenges, while dentists discussed the value of dentist mentorship as well as relying on guidance from other non-dental professionals. Parents of children with ASD often cite unmet needs and dissatisfaction with several aspects of health care services,[30] including lack of providers trained to treat their children[31] and difficulties communicating with their health care provider.[32] These factors can lead to strained patient-provider relationships,[33] and decrease likelihood of a successful health care visit. Enhancing provider opportunities to work with professionals from other disciplines may facilitate improved care. Additionally, parents of children with ASD report dissatisfaction with their care provider’s knowledge about community support services and their limited ability to address sensory issues and aggressive behaviors;[34] mentorship and inter-professional collaboration focusing on educating dentists in these particular areas would meet needs specifically documented by parents.

Interestingly, dentists reported the need to utilize parental expertise to promote successful encounters but parents did not discuss the value of their insight when discussing strategies

for success. This juxtaposes previous research which reported that healthcare providers had not requested parents' advice for treating their children or had ignored suggestions after they were made.[22] Previously, parents have also emphasized the importance of dental professionals listening to parental insight regarding child particularities and best practices.[29] Likewise, parents discussed the traits of dentists who were successful working with children with ASD (e.g., knowledge, understanding, experience) but dental professionals did not discuss these personal traits when talking about successes.

More research is needed to develop and examine the efficacy of interventions targeting preparatory strategies, clinical decision-making tools to enhance individualized tailored care, and inter-professional collaboration in the oral health care arena. Such research has the potential to improve oral care experiences for children with ASD and their caregivers as well as improve patient-provider relationships.

Although these findings highlight important strategies which may facilitate success during dental encounters, several limitations must be noted. First, inclusion in the parent group was based on parent-report of child's ASD; no confirmation utilizing gold-standard diagnostic tools was conducted. Second, because our study was conducted in southern California and included only four focus groups (n=2 parents and n=2 dental professionals), the results cannot be viewed as representative of all parents of children with ASD and dental professionals working with children with ASD. Third, because our focus groups were recruited from a convenience sample (parents) and snowball sampling (dentists), there may be selection bias in our study sample. Last, although there is a reported gender discrepancy in ASD diagnosis, with a 4:1 male-to-female ratio,[18] our parents all had male children and the experience of parents of girls with ASD may be different and is not represented here.

Conclusion

Based on this study's results, the following conclusions can be made:

1. Parents and dental practitioners report common strategies to allow for more effective and efficient dental treatment for children with ASD. These include:
    a. Home- and office-based strategies to *prepare* children with ASD for dental visits.
    b. Practitioner *flexibility* and willingness to *individually tailor* care and think outside the box when treating children with ASD.
    c. *Collaboration* with other professionals to develop strategies, improve autism-specific education, and obtain mentorship and guidance for working with children with ASD.
2. Incorporating home- and office-based strategies, individualized for a child's particular set of needs, are best practice for increasing the likelihood of a successful dental encounter for children with ASD.

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Table 1.

Focus Group Participant (Parent and Dental Professional) Characteristics

	Descriptive Characteristics	Focus Group Participants (n=9 Parents; n=7 Dentists)
		N (%)
Parent Participants	**Child Gender**	
	Male	9 (100.0)
	Child Age	
	5.0-7.11	4 (44.4)
	8.0-10.11	4 (44.4)
	11.0-13.11	0 (0.0)
	14.-18.11	1 (11.1)
	Child Communication Ability	
	Gestures	1 (11.1)
	Single words or phrases	3 (33.3)
	Sentences	5 (55.6)
	Screaming and/or yelling	0 (0.0)
	Unable to communicate needs or wants	0 (0.0)
	Child Race	
	White, Caucasian	5 (55.6)
	Asian	2 (22.2)
	Black, African American	0 (0.0)
	American Indian/Alaska Native	0 (0.0)
	More than one above	2 (22.2)
	Not reported	0 (0.0)
	Child Hispanic Status	
	Not Hispanic/Latino	5 (55.6)
	Hispanic/Latino	4 (44.4)
	Not reported	0 (0.0)
	Maternal Education Level	
	High School or GED	3 (33.3)
	College	2 (22.2)
	Graduate Degree or above	4 (44.4)
	Not reported	0 (0.0)
	Paternal Education Level	
	High School or GED	3 (33.3)
	College	3 (33.3)
	Graduate Degree or above	3 (33.3)
	Not reported	0 (0.0)
Dental Professional Participants	**Type of Dentist**	
	General Dentist	1 (14.3)
	Pediatric Dentist	6 (85.7)

Descriptive Characteristics	Focus Group Participants (n=9 Parents; n=7 Dentists) N (%)
Completed a Residency that specialized in CSHCNs	
Yes	7 (100.0)
Years in Practice (mean, SD)	23 (11.5)
Years in Practice Working with Children (mean, SD)	22.7 (11.3)
How were you educated in in dental school about treating CSHCNs?	
Lecture and Hands-on experience	4 (57.1)
Lecture only	2 (28.6)
None	1 (14.3)
Do you feel your education prepared you to work with CSHCNs?	
Yes	7 (100.0)
No	0 (0.0)
Do you feel that your education prepared you to work with children with ASD?	
Yes	4 (57.1)
No	3 (42.9)
How Frequently do you treat CSHCNs in your practice?	
Never	0 (0.0)
Rarely	0 (0.0)
Occasionally	0 (0.0)
Often	2 (28.6)
Very Often	5 (57.1)
How Frequently do you treat children with ASD in your practice?	
Never	0 (0.0)
Rarely	0 (0.0)
Occasionally	1 (14.3)
Often	2 (28.6)
Very Often	4 (57.1)
Treated approximately how many children with ASD in the last two years of practice	
10	1 (14.3)
50 - 99	2 (28.6)
100 or more	4 (57.1)

Table 2.

Endorsement of Key Overlapping Themes by Study Participants

		Overlapping Themes		
		Preparation n (%)	**Flexibility / Use of Creative Strategies n (%)**	**Collaboration n (%)**
Participants	**Caregivers (n=9)**			
	Overall	8 (88.9)	8 (88.9)	4 (44.4)
	Focus Group 1 (n=5)	5 (100)	5 (100)	2 (40.0)
	Focus Group 2 (n=4)	3 (75.0)	3 (75.0)	2 (50.0)
	Dental Professionals (n=7)			
	Overall	6 (85.7)	7 (100)	6 (85.7)
	Focus Group 1 (n=4)	4 (100)	4 (100)	4 (100)
	Focus Group 2 (n=3)*	2 (66.7)	3 (100)	2 (66.7)

**Note*. One dentist participated in both Focus Groups 1 and 2; his responses are only included in Focus Group 1 data, as presented in this table.