

## Listening to Parents: A Qualitative Look at the Dental and Oral Care Experiences of Children with Autism Spectrum Disorder

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**Abstract:** ***Purpose:** Children with autism spectrum disorder (ASD) experience various barriers to optimal dental and oral care. The purpose of this study was to conduct focus groups of parents of children with autism spectrum disorder and subsequent qualitative analysis of the interviews in order to better understand problems in dental and oral care encountered by children with ASD. **Methods:** Four focus groups, comprised of parents of children with ASD, ranging in age from three to 17 years old, were assembled. We took a semi-structured approach, facilitating discussion about home oral hygiene and professional dental care. Audiotapes were transcribed and independently coded by four investigators who then jointly identified themes. **Results:** There were three overarching, interrelated themes: (1) There is variability between children with ASD in how they tolerate dental and oral care and in what facilitates such care. (2) Parents want more extensive dental care for their children with ASD. (3) Each child's dental and oral care should be individualized based on parents' input about the unique characteristics and needs of their child. **Conclusions:** There is no "one size fits all" approach to dental and oral care for children with autism spectrum disorder. Parents are valuable partners in informing the unique dental and oral care needs of their child with ASD. (Pediatr Dent 2015;37(7):E98-E104) Received January 21, 2015 | Last Revision June 30, 2015 | Accepted July 2, 2015*

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Autism spectrum disorder (ASD) refers to a group of disorders of brain development, which are variably characterized by difficulties in social interaction and communication, restricted interests, and repetitive behaviors.<sup>1</sup> The Centers for Disease Control and Prevention estimates that one in 68 children has ASD,<sup>2</sup> which means that most dentists will encounter patients with ASD during their careers. Children with ASD, particularly those with communication, cognitive, and behavioral difficulties,<sup>3</sup> may encounter difficulty with home oral care and dental visits,<sup>4,5</sup> although some researchers have found that children with ASD have fewer caries than their typically developing peers.<sup>6,7</sup>

Common behavior-related barriers to dental care include the fact that children with ASD are prone to agitation, self-injury, and emotional dysregulation. Hypersensitivity to sensory input can also interfere with dental and oral care. These features make it difficult for parents to care for their children's teeth and for dental professionals to position, examine, and treat children with ASD.<sup>8</sup> Furthermore, children with ASD are often impaired in responding to social cues and communication; up to 40 percent of children with ASD do not talk at all.<sup>2</sup> Anxiety in unfamiliar environments, common in ASD, may exacerbate agitation and incite behavioral outbursts in the dental clinic.

Due to communication and cognitive challenges, children with ASD may not understand what is expected of them or be able to verbalize their needs during oral care or dental visits, thus limiting what can be accomplished and leading to the perception that these children are uncooperative. These factors may make it hard to find a dentist to provide care for child with

ASD.<sup>3,9,10</sup> McKinney et al. found that 15 percent of U.S. children with ASD had unmet dental care needs versus only six percent of American children overall with unmet dental care needs.<sup>11</sup> Furthermore, children with ASD who had intellectual disability or greater difficulty with communication, behavior, or physical function are more likely to have unmet dental need than their ASD counterparts without these characteristics.<sup>3</sup>

Recent surveys of parents of children with ASD have expanded our knowledge about barriers to home oral care and dental visits<sup>3,4,8-10</sup>; however, the underlying reasons for such barriers are incompletely understood. Qualitative research allows the opportunity to elicit new information and explore topics in greater detail. This methodology has been used previously to better understand barriers to other aspects of care for children with ASD such as factors affecting delays in autism diagnosis.<sup>12</sup>

With this in mind, the purpose of this study was to conduct a qualitative study of parents of children with autism spectrum disorder to gain further insight into these parents' and their children's experiences related to dental and oral care and learn from them how such care could be improved.

### Methods

Human subjects' approval to conduct this research was obtained from the Institutional Review Board of Seattle Children's Hospital, Seattle, Wash., USA.

**Setting.** Seattle Children's Autism Center (SCAC) is affiliated with Seattle Children's Hospital. It is the largest clinic focused on the care of ASD in the Pacific Northwest, serving approximately 3,000 unique patients who make over 18,000 visits each year. As the regional referral center, patients represent a diversity of racial, ethnic, and socioeconomic backgrounds. At SCAC, both public and private insurance are accepted and financial assistance is provided to the uninsured.

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**Participants.** Members of parent support groups at SCAC were asked by staff if they were interested in participating in a focus group to discuss their children’s oral health and dental care. This sort of participant recruitment is intended to select key informants and is common in qualitative research. Twenty parents volunteered (eight fathers and 12 mothers). Ages of their children with ASD ranged from three to 17 years old. Among these children with ASD, four were girls and 16 were boys and all had moderate to severe cognitive and/or behavioral challenges.

**Focus group procedures.** Four different focus groups were convened, each facilitated by two researchers who began each session by explaining the purpose of the study and obtaining informed consent for research participation. A semi-structured approach was taken, thereby allowing parents to direct the discussion content within the following topic areas: (1) their child with ASD; (2) their experiences with oral care at home, what difficulties were encountered, and what helped to facilitate oral care; (3) their experiences with dental care visits, what difficulties were encountered, and what helped to facilitate dental care visits; (4) the optimal dental visit for their children and what these parents wanted dental professionals to know about caring for their children. For example, the researcher would say, “Tell me about your child,” to introduce the first topic and “Let’s talk about toothbrushing in your house,” to introduce the second topic. Depending on the focus group conversation flow, the researcher might ask follow-up questions, such as: “Now, tell me about toothbrushing for your child with ASD.” Each focus group lasted approximately one hour. By the conclusion of the fourth focus group, thematic saturation had been reached, meaning that no new topics arose and parental input from prior focus groups had been repeated.

**Analysis.** Transcripts were professionally transcribed without mention of personal identifiers. Analysis of transcripts used a grounded theory approach. Each of the four researchers independently read and coded the transcripts. Coding refers to labeling segments of the transcript text with a word or phrase that relates it to the research objective. The researchers met on multiple occasions to review the transcripts in detail. Using successive iterations and consensus building among the researchers, codes were categorized and subsequently organized into themes and subthemes.

**Results**

We identified three overarching, inter-related themes: (1) There was variability between children with ASD in how they tolerate dental and oral care and what helps to facilitate/hinder such care. (2) Parents wanted more extensive dental care for their children with ASD. (3) Each child’s dental and oral care should be individualized based on parents’ input about their child’s unique characteristics and needs.

**Theme 1: There is variability between children with ASD in how they tolerate dental and oral care and what helps to facilitate/hinder such care.**

**Different factors affect oral care.** Every child with ASD is different and there is variability in the types of challenges that make home oral care difficult. Some children had trouble with toothbrushing because they were orally averse, as this parent’s comment reflected:

*“I was totally unable to get into her mouth for the first several years of her life because she was so sensitive. She is also not communicative so it doesn’t help to explain.”*

Another issue that interfered with oral care was that parents of children with ASD can be overwhelmed by their children’s other problems and needs, such that home oral care does not always receive the attention that it might otherwise. Distracted by concerns for their children’s developmental challenges, parents did not always think about routine matters like toothbrushing. Regular therapy visits and home behavioral programs consumed parents’ time and energy. Faced with such stress, dental and oral care fell lower on the priority list. Parents spoke of having little energy left over for oral care, as evidenced by this comment from a parent:

*“Brushing teeth falls at the bottom of my priority list. There are so many stressors. We’re all exhausted by the end of the day.”*

**Parents rely on a variety of strategies to facilitate oral care.**

For better or worse, some parents physically restrained their children in order to brush their teeth, as this mother described:

*“Up until he was nine years old, we had to forcibly hold him down. He’s 11. We still have to brush his teeth for him.”*

Having a specific routine helped to a degree, as this parent explained:

*“It is not going to happen unless we do it the exact same time of the day, every day. You can’t just brush his teeth in the morning one day and the night the next day; that will just make him scream and cry. But if you do it at the exact same time at night, then he will cry if you don’t do it. I can only get a few swipes—he will stick his tongue out and in the way, and it doesn’t matter if I use the electric toothbrush or not, so I use the electric one because I think it does a better job.”*

Over time, some children were able to assume more responsibility for oral care, although most parents continued to help their children brush, as demonstrated by this comment from a parent:

*“It took a long time, and now she will independently take a vibrating toothbrush and move it around in there, and then we have to do it for her. I am glad that we have that, because I feel like we are doing something.”*

Other parents also reported that their children seemed to better tolerate a battery-powered toothbrush. Some children preferred the vibrating sensation over manual brushing, while other children would not tolerate any form of toothbrush or toothpaste. Some children would accept a toothbrush dipped into fluoride mouthwash but not the use of toothpaste.

Two parents of school-age children reported that it was helpful to have toothbrushing incorporated into their children’s school therapy program, as these comments, made in different focus groups, revealed:

*Parent 1: “We also send him to school with a toothbrush and toothpaste. And so that is part of the program they work on there. That gives him like two times a day to have some exposure to toothbrushing.”*

*Parent 2: “I presented a whole thing at the school on toothbrushing at school so they would start to do that at school. I did because it was such a struggle at home, and I wanted someone else to be working on it, too, and for him to see his peers doing it.”*

**Dental visits are challenging.** Parents stated that they considered dental care to be important for their children with ASD, yet dental visits could be challenging for a number of reasons. As children grew older and sometimes larger and stronger than their parent, even getting a child with ASD to the dental clinic could be difficult, as this mother addressed:

*“I never go alone. It is a safety thing. I hire an aide to go with us or my husband goes too, because just getting him into the building is hard.”*

**The waiting room posed a particular difficulty for a number of children with ASD and their parents.** Often, this was because of these children’s limited capacity to wait without becoming overtly anxious and agitated. One parent said that, for her child:

*“Longer than five minutes waiting and we are done.”*

Toys and activities in the waiting room that might appeal to typically developing children are less likely to interest children with ASD, as this parent expressed:

*“Anything that you would think would make it easier like a toy or something—that is just going to piss him off.”*

Other parents made the following comments concerning what was stressful about being in the waiting room:

*“At the dental clinic, they had this room with all of their computer stuff, and it had a window, and he loves windows. He kept running in there where it was obvious that kids weren’t supposed to be there.”*

*“There was a pile of paper in the waiting room. My daughter likes to shred paper...we go through thousands of pages of paper every week. My daughter just shreds paper all day.”*

*“It was really hard to contain him—he is getting really big and fast. He doesn’t understand when you say, ‘just stay here and play with these toys.’”*

*“I plan it so we go first thing in the A.M., so we don’t have to wait. Because if we have to wait, forget it.”*

*“The optimal thing would be to go from the car to the exam room and then leave as soon as it is done, because it is the waiting that is so hard for him and for everyone else in the waiting area.”*

The idea of waiting in the car until it was time for the dental examination was repeated by other parents.

Waiting was hard on parents for other reasons. They spoke of feeling awkward and embarrassed when their children acted up in public places. One parent said of this:

*“Everywhere you go; everyone is staring at your child.”*

They also worried that they were being judged as bad parents and being blamed for their children’s behavioral outbursts, as indicated by this parent’s comment:

*“The thing that is really hard about being the mom of a kid with behavior problems is that you are always being blamed. It is really hard. You just don’t need another time where you are not measuring up. I am stressed enough; now I’m getting complaints because my child isn’t behaving right. This is my life.”*

**Behavior management is not the same for children with ASD.** The usual behavior management strategies employed for typically developing children, such as negative consequences for bad behavior and rewards for positive behavior, are often less effective for children with ASD. That didn’t stop strangers from giving unsolicited advice to parents of children with ASD about how to discipline their screaming or otherwise ‘misbehaving’ children—for example, parents spoke of being urged to spank their children. Parents commented:

*“I can’t make him stop. I have less control than you think.”*

*“The same rules don’t apply to kids with autism, and that should be okay. It doesn’t feel like it is okay sometimes.”*

It was hard for some parents to request special accommodation for their children, such as asking for the first appointment of the day. This parent explained:

*“I feel bad asking for special treatment. I already have a kid who is so difficult. You so much want to fit into society—so asking can seem like making special demands.”*

**What hinders or helps during a dental visit varies from child to child.** Once the waiting was over and the dental visit itself had begun, the situation improved for some children. A dentist and staff who are experienced in caring for children with ASD and are willing to accommodate a child’s specific interests helped facilitate a more successful dental visit for certain children.

*“I am really pleased with the way our dentist works. The dentist started with a really, really slow routine to make him comfortable. The chair goes up and down. My son loves water and he loves to suck it up in the silly straw, and then they said, ‘let’s look in your mouth and count your teeth.’ The first time they didn’t get any cleaning done...it is still really hard to get his teeth cleaned.”*

Parents recognized that some children with ASD are more capable of tolerating new experiences if they are adequately prepared; this could involve pictorial social stories to show their children beforehand what to expect during a dental visit, as suggested by this parent’s comment:

*“What helps my son is social stories, preparing him using a book I created called Going to the Dentist, with actual pictures of the dentist’s office and the people he is going to see.”*

Parents, however, acknowledged that, even with adequate preparation, it wasn’t always possible for their children to actually undergo an oral examination or cleaning during a dental visit, as these two parents discussed:

*Parent 1: “Once they want him to open, it can go downhill from there. Playing with the tools is okay, but when they want him to open...”*

*Parent 2: “Our son is just like that. They let him play with the tools and then, when they want to look in his mouth, it is all over. They just count his teeth and then a little bit of fluoride and that’s it.”*

A single negative stimulus could prematurely end the dental visit:

*“He is afraid of balloons, and, for a while, it extended to rubber gloves, and one day the hygienist went to put on gloves, and he freaked out, and I said, ‘we are done today.’”*

*“When we entered the exam room, there was a papoose on the dental chair, and that has never been successful with her. I didn’t notice it right away but (my child) did, and the next thing you know, she was out at the elevator. She’s gone.”*

Although some children would not tolerate the papoose board, other parents reported that their children tolerated the dental visit better if they were restrained in a papoose. This was one more example of the variability in what worked best for dental care among children with ASD.

Likewise, parents were clear that strategies effective for some children with ASD were not helpful for others. One parent said:

*“Every kid with autism is going to respond very differently to being at the dentist.”*

Social stories worked for some but were completely ineffective for other children with ASD. Taking time to explain to a child what was happening during a dental visit could actually be counterproductive, because it could make some children more agitated. There were children for whom an expedited dental visit was most helpful. “There is no time for pleasantries,” one parent said, referring to the need to get through the dental examination/treatment as quickly and efficiently as possible. This mother explained:

*“With some children with ASD, you really can discuss and show pictures and rationalize. I don’t think with my son that any preparation is going to make it easier. When we go to the dentist, they get us in and don’t monkey around, and they get it done. They do a very quick, fast job; I don’t know how thorough, but thorough enough.”*

Even so, these visits were difficult, as she went on to describe:

*“He is in the dental chair and he’s gagging. He probably feels like he is being tortured. It’s scary. He’s got the big stick in. They are holding him down, and they are holding his feet, and the dentist is doing the best she can to clean his teeth. It’s very fast. It is like an emergency room situation. We have like five minutes to get this done. And then he comes out of it. Exhausted and sweaty, we go home and, I think, ‘Thank God that’s over.’ I mean, I try once a year. I just hate it so much that I even put it off, and then I feel negligent. So it is just this big vicious circle.”*

Other parents also described stressful dental visits:

*“My son had an infection and needed to have a tooth pulled. He can’t express himself, so I don’t know if he was numbed up properly. I think he went into shock. We all had to lie on top of him. He was dripping in sweat, and his pupils were dilated, and then he screamed and screamed like he was being tortured.”*

**Theme 2: Parents want more extensive dental care for their children with ASD.** In addition to concerns about the traumatic nature of dental visits for some children with ASD, it was a point of frustration for parents that so little dental care seemingly was accomplished, as these comments demonstrate:

*“We have a children’s dentist, but he won’t sedate (my son) or use a papoose. It’s awful. He just screams his head off. He has never had X-rays. All the dentist does is fluoride treatment.”*

*“I wish we could get the full exam. I want X-rays to make sure there are no cavities. We just get fluoride and then leave.”*

**Parents want more dental care to be accomplished with less trauma.** To do so, parents wanted to discuss options for restraints and sedation, and their respective risks and benefits, with their dentist. A number of parents had inquired with their dentist about sedation in order to accomplish more, in keeping with what occurred at dental visits for their typically developing children, but had been told that sedation was too risky. In addressing her desire to have her son sedated for dental care, this mother spoke of fairness:

*“You know with my (typically developing) girls, they have their regular visits and orthodontics. They have gotten really excellent dental care and (my son with ASD) deserves really excellent dental care, too.”*

Despite hearing about risks, some parents believed it would have been less traumatic if their children were sedated for dental care:

*“I thought they were going to sedate him, but the dentist said there are risks involved. My son ended up with a bloody lip and was so agitated. It was traumatic for everyone, including the dentist.”*

*“If we could do something next time to make it easier, I want him knocked out completely. The dentist told me he doesn’t like to do this due to the risks, but there are risks to having tooth decay, too.”*

*“The trauma that (my son) and the dentist went through could have been avoided if they would have put him to sleep. I think he needs to be sedated.”*

On the other hand, one mother of a teenage boy expressed that she didn’t think sedation would be effective or safe for her son. She preferred taking him to a specialty clinic that was prepared for her son’s behavioral challenges, as she discussed:

*“The reason that I have it better is because of where I go, and they are used to taking care of special needs. There are enough people there to help. I can literally stand back, and there are a lot of men that work there, which seems to be helpful because they are stronger. They know when the appointment is set that they are going to need not only the dentist but two to three other people to wrap him and hold him.”*

This mother’s comment about being able to stand back speaks to a recurrent concept that arose during these focus groups—some parents did not want to physically restrain their own children at dental visits. This parent explained:

*“When you are physically holding your child down and forcing them to do something that they are terrified of, that is not natural. It is not what parents are supposed to do. You just don’t hold your kid down and make them do something, it is just not okay. You have to live with your child for the rest of your life, and they have to trust you.”*

**Theme 3: Each child’s dental and oral care needs to be individualized based on parents’ input about the unique characteristics and needs of their children.** Parents told us that there is no best way of providing dental and oral care that could be applied to every child with ASD. Given the variability among children with ASD, parents felt it was particularly important that their input be sought in planning and that they be present during a dental visit. Parents expressed frustration that providers made assumptions about how their children with ASD should behave:

*“I do feel there is a lack of understanding of the challenges that we face with our kids. Like when they say, ‘we want her to sit still,’ and I say to myself, ‘do I bother telling them she is not going to do that?’”*

**Parents know their children.** Many parents shared stories about how dental and medical providers had either not asked or ignored parents’ advice about the best way to approach their child’s care. For example, one parent specifically requested that a pulse oximeter not be placed on her daughter’s finger because her daughter did not tolerate having her hands touched. However, this advice was ignored and the pulse oximeter was placed on her finger anyway; the child then became so upset after her hand had been touched that it took hours to calm her down. The girl’s mother felt frustrated that the pulse oximeter probe had not been placed on her daughter’s foot, as she had requested in the first place. Another parent spoke of her experience when the dentist brought out a papoose to restrain her child, even though her child had never tolerated one:

*“It set us back six months in making progress towards (her daughter) getting used to dental visits.”*

**Parents want to provide input.** Parents spoke about the importance of being able to provide input on the care of their children with ASD, as demonstrated by these parents’ comments:

*“I didn’t need the doctors to listen so much with my other kids. But with (my son with ASD), I really need to be listened to.”*

*“I am the expert on my child. You may have an MD or DDS or whatever license that you have, but you are not the expert on my particular child, so things should not be done a certain way. I am very clear about advocating for my child. This is how it is going to work, and I am not willing to try it another way.”*

*“The things that I am telling the dentist, they do matter. It matters that you can’t touch him a certain way.”*

*“I do wish there could be a cover page on the chart that said, ‘this kid has autism, ask the parent.’”*

However, some parents did not feel empowered to speak up about their children’s needs and preferences. Others expressed surprise at the possibility that a dental provider would actually ask such questions. One parent said:

*“No one has really ever asked me, but I would be thrilled if someone wanted to know if there are special things we need to do differently because of his autism.”*

Parents wanted the dentist or staff to ask in advance of the visit about how ASD specifically affected their children and how the visit could be made to go as smoothly as possible. Consider these comments from parents:

*“I want them to ask: ‘what is the best way to proceed with your son?’”*

*“I think they need a list of triggers and then they need to review those before the kid arrives.”*

*“They should ask about individualized preferences of each kid with autism.”*

When parents finally had a plan that worked for their child with ASD at the dentist, their relief and gratitude were readily apparent, as this parent’s comment indicated:

*“When we take our child in for a dental visit, it feels so good to be welcomed by a team who really knows us, is prepared for us, and partners with us. This has taken years to find and shape, but I am confident has led to an easier time for staff, less stress for me, and better outcomes for my child. It is not an exaggeration to say that they are heroes to our family.”*

As parents within focus groups discussed the various important questions to be asked in advance of their children’s dental visit, they concluded that these could be consolidated into a pre-visit questionnaire or consultation (Table). Some parents expressed interest in helping their dentist design such an intake process.

Table. DEVELOPING AN INDIVIDUALIZED DENTAL CARE PLAN FOR CHILDREN WITH AUTISM SPECTRUM DISORDER

1. Questions for parents before the dental visit
2. Child’s developmental status, behavioral issues, and other diagnoses
3. Child’s previous experiences with and tolerance of dental and oral care (or for the first dental visit: how the child tolerates a haircut or other health care appointments). What works best?
4. Current home oral care regimen and barriers/facilitators
5. Parents’ concerns and goals for the dental visit
6. Whether preparation with social stories or other strategies is helpful
7. Best time of day for a dental appointment
8. How the child deals with waiting and the waiting room and potential alternatives (e.g., waiting in the car or first appointment of the day)
9. Factors that could exacerbate or diminish a child’s behavioral problems in the dental office (e.g., explaining every step in advance could help some children but make others more anxious and agitated)
10. Specific preferences—toothpaste flavor, sunglasses or not, papoose in the room or not, and desired degree of parental involvement in positioning/restraining the child, when and how to provide anticipatory guidance (e.g., in person or later on the phone or, as one mother suggested, left on voicemail)
11. Questions, concerns, preferences, and expectations regarding sedation, general anesthesia and restraints

**Parents want to be able to focus on what dentists have to say without distraction.** Just as there was a preference to provide information about their children in advance of the visit, some parents also wanted to delay necessary education, anticipatory guidance, or discussion with the dentist until after they had returned home. This was because these parents found it hard to have discussions with providers when their attention needed to be focused on their children. Parents expressed it this way:

*“Talking with me is really hard, because I am so preoccupied keeping my son happy. Doing it by phone would be good. That should be done before and after, on the phone. People are talking to me, and (my son) is just bashing his head into the wall.”*

*“The more you can talk without the kid being there, the better it is, because that is really hard when you are in the middle of a tantrum.”*

## Discussion

Similar to other researchers,<sup>4,8-10,13,14</sup> our findings indicate that children with ASD and their parents encounter a number of challenges and stressors surrounding home oral care and visits to the dentist. Our study is the first to employ qualitative methods to better understand how dental and oral care could be improved for this population. Using an open-ended approach allowed a deeper understanding of the factors influencing dental and oral care for children with ASD. We also captured a glimpse of the real-life challenges experienced by these families in their pursuit of dental and oral care for their children with ASD. Our results emphasize the importance of considering the individual characteristics and needs of children with ASD and of dentists partnering with parents to optimize care.

Dr. William Osler said: “Variability is the law of life... and no two individuals react alike and behave alike.”<sup>15</sup> This seems to be particularly true of children with ASD. Even within this group of children with moderate to severe behavioral and cognitive challenges associated with their ASD, there was variability in how they tolerated dental and oral care and in the factors that influenced such care. What was helpful for one child, for example, use of a papoose, could fail completely for another.

Parents told us that children with ASD should not be expected to behave like typically developing children or even like one another when it comes to dental and oral care. Relying on common dental behavioral guidance techniques could be counterproductive when applied to children with ASD. For example, using the common tell-show-do approach during a dental visit could unnecessarily prolong a child’s agitation and stress. Given the degree of variability among children with ASD and these children’s difficulty acclimating to new experiences, the emphasis should be on adjusting the dental care environment to accommodate the child’s individual needs.

We know little about the extent to which this happens in practice. However, in a survey of general and pediatric dentists, approximately two-thirds of both general and pediatric dentists said they offer special scheduling arrangements for children with ASD, but only eight percent of general dentists and 18 percent of pediatric dentists said they have a special office setup for these patients.<sup>16</sup>

Some parents found dental visits to be very challenging endeavors and, in the end, were upset that only what they considered to be minimal dental care was accomplished. These parents spoke of wanting more extensive dental care for their child with ASD and, if necessary, using sedation or general anesthesia (GA). These perceptions of under-treatment may in part underlie population-based reports of unmet dental care need among children with ASD. Requesting sedation or GA is not unrealistic, given how stressful and even traumatic the dental care experience could be for some children with ASD. However, sedation and GA have risks and require additional staff, resources, and possibly a referral to a different site.<sup>17</sup> Nevertheless, parents wanted to discuss various options with their child’s dentist to weigh relative risks and benefits and have their previous experience and input be considered in the decision-making process around sedation, GA, or restraints. Loo et al. identified predictors of GA and protective stabilization for dental care in children with ASD,<sup>14</sup> but we could find no study that characterized parental preferences or addressed shared decision-making (i.e., between parents and the dentist) about sedation, GA, or restraints.

Some authors have concluded that dentists need to better understand ASD behavior management techniques.<sup>18,19</sup> Dentists have acknowledged that they receive little education in the care of children with ASD.<sup>16</sup> Yet, being knowledgeable about ASD represents only a small part of the solution to improving care for children with ASD. Our results indicate that parents are perhaps the most valuable sources of information about the individual needs and appropriate accommodation to assist their child with ASD. Parents bring substantial experience and insight about their child to the dental office and want to be involved in facilitating their child’s dental and oral care. Our findings add further insight to the recommendations of other authors about the importance of flexibility and parental involvement in planning dental visits for children with ASD.<sup>18, 20,21</sup> Some parents are comfortable taking the initiative to advocate for their child, while others parents need to be encouraged and empowered. Seeking input from parents may be a paradigm shift for health care providers who are more used to educating parents than being educated by them.

During these focus groups, parents described information that they believed was important for dentists and their staff to know prior to providing dental care for their child with ASD. Such data could be collected in a pre-visit questionnaire or added to a pre-existing instrument<sup>21</sup> and then used by the parents and dentist to jointly create an individualized dental care plan for the child. This care plan would become part of the dental chart, reviewed prior to each dental visit, and updated regularly. Factors to consider in developing such care plans, derived from parents’ input in this study, are listed in the Table.

Certain limitations to this project bear mention. In interviewing members of an ASD parent support group, we tapped into a rich source of key informants; however, these participants may not represent the entirety of parents of children with ASD. We also conducted these interviews in one institution in one city, although it was the regional referral center for autism care. Our findings may not reflect experiences of parents in other geographic areas. However, the value of qualitative research is that it provides a basis for further research on other populations.

## Conclusions

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

1. Children with autism spectrum disorder and their parents encountered a number of challenges and stressors surrounding home oral care and visits to the dentist.
2. What hindered or helped during a dental visit varied from child to child with ASD. An individualized approach to planning and providing dental services is needed to optimize dental and oral care for some children with ASD.
3. Parents brought substantial experience and insight about their child to the dental office and wanted to be asked about and involved in facilitating their child's dental and oral care. While 'ask the parent' is a seemingly simple directive, in some families' experiences, this does not happen often enough in either medical or dental care.
4. Some parents wanted more extensive dental care for their child with ASD, and, to that end, they wanted to:
  - discuss various options for sedation, GA, or restraints with their child's dentist;
  - weigh relative risks and benefits; and
  - have their previous experience and input considered in the decision-making process.

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