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Parents' perceptions of dental care challenges in male children with autism spectrum disorder: An initial qualitative exploration

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Abstract

Background—Many children with autism spectrum disorders (ASD) experience barriers to oral care in the dental office setting. The purpose of this study was to provide an increased understanding of these challenges experienced during oral care in the dental office by children with ASD.

Method—This study was part of a larger mixed methods design and builds on quantitative results from a survey of parents of children with ASD ages 2–18 in which parents reported difficulties with access to care, sensory processing, and uncooperative behaviors. For this study, we conducted two, three hour, focus groups of parents of male children with ASD age 5–18 years in order to explore the survey results in greater depth. Focus group transcripts were analyzed using a template coding approach based on the three domains of office-based oral care challenges identified in the first phase (survey).

Results—Several related themes emerged including: (1) *Access*: “Difficult to find the right dentist”, (2) *Sensory sensitivities*: “All the sensory devices just make him so uncomfortable”, (3) *Restraint*: “It looked like they were torturing him”, and (4) *Drugs*: “A mixed bag”.

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Conclusions—The qualitative findings from this study both confirmed our previous survey findings and expanded upon them. These findings can help professionals better understand the challenges experienced by children with ASD and their parents as well as help identify priorities for planning efforts to address the oral health-related needs of this population.

Keywords

Autism spectrum disorder; health care; dental care; oral care; oral health; occupational therapy; qualitative methods

Introduction

It is well-established that oral care is an important component of pediatric health care. Poor oral health and the diseases that may result from it can negatively affect one's health and quality of life (Casamassimo, 1996; HHS, 2000). Despite the importance of oral care, disparities exist for children with special health care needs in access to and practice of oral care in the United States, with dental care being the most frequently cited unmet health care need (Lewis et al., 2005). The majority of research indicates that children with ASD exhibit high prevalence of poor oral health, as measured by prevalence and severity of caries (DeMattei et al., 2007; Jaber, 2011; Kopycka-Kedzierawski & Auinger, 2008; Marshall et al., 2010), despite a small number of contradictory studies (Fahlvik-Planefeldt & Herrstrom, 2001; Loo et al., 2008; Morinushi et al., 2001). Although not a direct cause of dental deficit, behaviors and life factors prevalent in the ASD population are associated with increased caries (Marshall et al., 2010).

Despite the increase in ASD, now reported to be 1 in every 68 children (CDC, 2016) and a boom in ASD research, there is limited research regarding the oral health care challenges experienced by children with ASD. Previous research, based primarily on parent- or dentist-report questionnaires, suggests that children with ASD face many barriers to oral health, including but not limited to: inadequate numbers of dentists trained and willing to work with children with ASD (Brickhouse et al. 2009; Weil & Inglehart, 2010), impairments in child communication (Marshall et al., 2007), uncooperative behaviors (Brickhouse et al., 2009; Loo et al., 2008), difficulties with sensory processing (Stein et al., 2011; 2012; 2013), and financial issues (Brickhouse et al., 2009).

This qualitative study, which was part of a larger mixed methods design, seeks to understand how families of children with ASD experience challenges with dental care. This study builds on findings from a previously published study of barriers to quality dental care for children with ASD in which quantitative methods were used to identify the types and degree of oral care challenges that affect children with ASD (Stein et al., 2012). These included findings related to access to care, challenges in the home, and challenges in the dental environment. Using the strengths of qualitative methods, this study explores how caregivers experience dental care challenges for children with ASD and thus expands upon a limited research base that can be used to improve patient-centered care.

Methods

This qualitative study included two, three hour, focus groups of parents who had completed a survey regarding challenges to oral care for their children with ASD (Stein et al., 2012). Focus groups were selected as a method to have parents respond to one another regarding common experiences that can result in a more complete discussion than might have occurred through individual interviews (Padgett, 2012).

This study was approved for human subjects by the Institutional Review Board of the University of Southern California Health Sciences and informed consent was obtained from all participants.

Participants

Parents were recruited from the Southern California area via brochures and flyers posted at local school districts and two large urban hospitals. Focus group participants were recruited through consecutive sampling of the parents who met inclusion criteria (had at least one child with ASD between the ages of 5 and 18 years at the time of recruitment and were fluent in English) and indicated they would be willing to participate in a focus group. Recruitment yielded 13 parents who accepted and were scheduled to participate in one of two focus groups that took place between April of 2011 and 2013. Target recruitment was 10 caregivers; as it is common for participants to miss a scheduled and confirmed focus group, a total of 13 parents were recruited. Nine of the 13 parents attended the scheduled focus groups and were consented and participated in one of the two groups. No reasons were provided by the four caregivers who did not attend, see Table 1 for caregiver and child information. Focus groups had 4–5 participants per group; given that we believe that parents have a great deal to contribute regarding the dental care of their child with ASD, groups were purposely kept small in order to allow all participants to share in the discussion. Participants were provided with a small gift card.

Data collection

The two focus groups were semi-structured and utilized the cornerstones to focus group success as outlined by Cote-Arsenault and Morrison-Beedy (2005), including: keeping the purpose of the study as the driving force, establishing an environment conducive to interactions, and utilizing skilled personnel (focus groups were led by LISD and SAC, both of whom have had formal didactic and hands-on training in interview and focus group methodology). Semi-structured interview questions were created to elicit details about the dental care-related challenges experienced by children with ASD. 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 included prompts about challenges experienced during professional dental care in the three domains identified in previously conducted survey: access to care, sensory processing, and behavioral difficulties (Stein et al., 2012). The focus group moderator was instructed to further probe any other salient experiences that participants wished to discuss.

The moderator gave a brief presentation of the aims of the focus group and then began the focus group with the first semi-structured question. Although the question list was used to guide the discussion, the moderator was instructed to further probe participants' experiences based on participants' verbal and nonverbal responses. Each group lasted approximately 2.5–3 hours, was recorded and transcribed verbatim, and took place in Southern California.

Data analysis

Thematic analysis was conducted by analyzing transcripts using a template coding approach (Crabtree & Miller, 1999). Template codes were based on the three domains of professional dental care challenges covered in the survey. To do this, the research team independently read and coded a single focus group transcript before meeting to discuss the provisional code list and add any emergent codes. Using an agreed upon combined list of codes, team members went back to the original transcript to independently code before meeting to compare coded materials. The same process was then used for the transcript from the second focus group. Discrepancies in coding were resolved through discussion until a consensus was reached and a more in-depth understanding of parental challenges to dental care was achieved (Padgett, 2012). Initial inter-rater agreement for codes was 98%. Themes were then developed that reflected the overall responses of the majority of participants. Sub-themes that reflected how different subsets of family members experience the main themes were also identified and illustrated through the use of illustrative quotes. Any direct disagreement among participants was also noted and included within the findings.

Strategies of rigor in qualitative research that were utilized to support the credibility and trustworthiness of these findings included: co-coding, peer researcher debriefing, negative case analysis, consensus-driven thematic development, and maintaining an audit trail for analytic decisions (Padgett, 2012).

Results

Four themes regarding professional dental challenges emerged from parents of children with ASD. These included barriers related to access to care, sensory sensitivities, use of restraint during care, and utilization of pharmacological methods during care. These themes are reflective of the responses of the majority of participants, manifest in different ways as presented by sub-themes and quotes below; any direct disagreement of majority themes by participants is also explicated below.

Access: “Difficult to Find the Right Dentist”

All parents reported that it was difficult to find the right dentist for their son with ASD. Their stories clustered into four sub-themes, including (1) dentist rejection, (2) dentist misrepresentation, (3) referrals, and (4) cost.

Dentist rejection—Dentists rejecting or refusing to treat children with ASD was often blamed on dentists' either not being able to “handle the [child's] behavior”, the dentist's report that he/she “doesn't really do *those* kids”, or because the dentist had “no awareness on how to handle a special needs kid.” This type of rejection often led to parents and children

going to multiple dentists before finally getting a referral or finding a dentist they liked. It took one parent multiple years and two previous dentists before they found

...the one that we love. She is a pediatric focused dentist although I'd love to go there too! So yeah, we are just really grateful because the first two that we went to were, uh, I don't even know that I would go to them... [because] it was so awful."

Dentist Misrepresentation—Even more distressing to parents was dentist misrepresentation which was described when one parent explained that "I would call around and they would say 'Oh yeah, bring him in, not a problem.' And I would bring him in and you know...it was awful". Similarly, another parent described how

They claimed that they catered to special needs kids so that's why we went. We live in *** and that's why we went all the way out there, but after that, it was just um, it was just one of those, like, I'm never gonna put my kid in that situation again [child in papoose board with multiple people trying to restrain him, son screaming and crying, and mother crying in the room], as much as I can help it!

When asked what they thought dentists could do to make dental care easier for children and their families, one parent even responded "Know how to deal with autistic kids!" which was met with agreement from the rest of the parents in the focus group. Parents were especially concerned about dentist misrepresentation because they felt that "you don't want to create those really negative [first experiences] because then it is really hard to get him back in."

Referrals—Parents also noted that referrals were important in finding the right dentist, although obtaining referrals could be challenging. Referrals were reported to come from other healthcare professionals, extensive research conducted by the parent online (e.g., reaching out to other parents via autism support group websites), or by word-of-mouth. Several parents reported "being on their own" in regard to finding a dentist for their son, stating that they would often search online for dentists and then call the office to check willingness to treat a child with ASD. For one parent this worked well, but other parents reported that this strategy had led to *dentist misrepresentation*. Parents were more likely to trust the recommendation of another parent of a child with ASD, often found online via websites such as Autism Speaks. Referrals were also reported to be made by healthcare professionals such as dentists (following rejection) and primary care physicians; however, these referrals were most useful if a good rapport existed between the parent and physician. For example, one parent explained that her son's pediatrician had recommended a pediatric dentist and that it had worked out well; however, another parent reported that "we went through a couple of physicians because they didn't really recognize autism...I probably wouldn't have trusted their recommendations".

Cost—Lastly, cost was an important factor in accessing care for children with ASD. Parents noted that obtaining access to dental care was more expensive for their child with ASD. One mother described how as soon as she thought her son had ASD she "...changed my insurance from a HMO to a PPO because I knew if I stayed in the HMO it was going to be really hard to get a child-centered dentist, much less one with experience with special needs kids", and another stated that "I changed dentists from the original one we found [covered

by insurance]...I like her. She's not very, um, cheap, but she's great." Another mother explained that she took her son to the dentist more frequently, specifically, "...he went to the dentist every three months for the first four years...it was just the initial getting into his mouth and that's why we went every three months for so many years"; unfortunately, these extra visits were "more expensive because insurance doesn't cover it". Lastly, one father reported that after his son's traumatic first experience he found "an anesthesiologist who hires dentists as opposed to dentists who would have to hire an anesthesiologist" who has been successful in providing care to his son. However, this type of treatment was very expensive and "off our plan, so, uh, we had to pay for this. But, like I said, because of the work they're able to get done [e.g., X-rays, dental cleanings], it was worth it." Unfortunately, not all parents had this level of financial flexibility, as explicated by one mother who stated that

We went to this really good pediatric dentist and she's willing to take my son, but...it's like a thousand dollars more, even when we have a dental plan, we still have out of pocket, so, so, I have to keep going back to *** [even though previous bad experiences], so that's why we stay there.

Sensory Sensitivities: "All the Sensory Devices Just Make Him so Uncomfortable"

Sensory sensitivities were also described by multiple parents as causing challenges at dental appointments. Some parents explained that their children were over-responsive to all sensations, such as this mother who stated that "my son is very sensory oriented...once he steps in that environment he feels uncomfortable...all the sensory devices will just make him so uncomfortable." Likewise, parents endorsed multiple difficulties with the tactile (touch) and gustatory (taste) senses, as well as problems with visual (sight), auditory (hearing), and vestibular (movement) stimuli at the dentist.

Tactile Stimuli—Multiple parents commented that getting equipment or the dentists' fingers into the child's mouth was extremely difficult and the "hardest thing". For example, one parent took her son to the dentist every three months for many years to acclimate him to letting the dentist touch in or around his mouth. For another parent, even touch "getting near his lip area has been a challenge, even to this day...He knows starting from the waiting room. You know, so, it, we haven't had a positive experience unfortunately." Difficulty with tactile stimuli in the mouth was not only problematic in the dental office, but was also manifested in oral care practices in the home. For example, one parent explained that

...it's hard to get a toothbrush in his mouth and when we do get a toothbrush in his mouth he will only let us brush the sides, like the outer sides, but you can't do like the inner sides. So anything that would include touching his tongue or that inside area it's nearly impossible to do...We've tried different types of toothbrushes um even like the little finger ones that you can stick in there or the ones that light up. He has one that uh lights up um and it forget the vibrating ones those are just out of the question for him...Um, it is just a very difficult experience.

Similarly, another parent shared a story of how her son "scrapes everything off his teeth, so, he doesn't like anything to touch his mouth" during mealtimes, indicating that this sensitivity is generalized to all tactile stimuli, not just that for oral care.

Gustatory Stimuli—Parents consistently mentioned the taste of the paste used during cleanings as well as the taste of the fluoride at the end of dental cleanings as a source of problems. Multiple parents told stories of how their sons were “spitting and wiping his teeth” or “spitting and stuffing his mouth with his t-shirt, you know, trying to clean it off” during the cleaning and fluoride application. Waiting an hour to eat after fluoride application also caused difficulty, with children wanting to eat after the dental appointment or receive food rewards, but also because, as one mother put it, “he wants to get it off [his teeth] and it drives him crazy and he’s very upset about it.”

Auditory Stimuli—Difficulties with noise volume were mentioned as a problem for dental care. Parents described the difficulties their child with ASD experienced at all aspects of the appointments including the waiting room, receiving care in open dental bays with other children around, and even when receiving care in a private dental room due to the noises of the dental equipment. As one mother put it,

I’m wondering if they’re working on equipment that’s less noisy. I think that would be good for everyone not just autistic kids because that zzzzzzzzz noise is just...it bothers me because I associate that with I know they’re going to do something like that zzzzzzzzz. I know it’s going to be uncomfortable and I know my son hates that noise...

Visual Stimuli—Bright lights shining into children’s eyes were another sensory feature of the dental environment that caused discomfort to children with ASD. Strategies implemented by parents such as use of sunglasses or hats were only successful for some children due to co-occurring tactile sensitivities. One mother explained that she’s “tried the sunglasses and all of that, but he doesn’t like having anything on his face...he doesn’t have the bright light [shining in his eyes when he’s wearing sunglasses] but then he has something on his head, so it’s kinda a wash, I think, for him.” Another mother explained that her son felt the same way, “So, it’s like, pick your poison”, bright lights or something touching her son’s head.

Vestibular Stimuli—For some children with ASD, movement can cause anxiety and distress. This occurred at the dental office once the child was seated in the dental chair and the dentist attempted to recline it. As one mother put it, “...the chair was an issue going back, um, leaning back was an issue. He got more anxious when he had to lean back. I don’t know...he felt a little vulnerable”.

Restraint: “It Looked Like They Were Torturing Him”

All parents recounted the use of restraint during dental care, provided either by themselves, their spouses, dental professionals, or often all of the above. Parents explained that they commonly utilized strategies such as sitting in the dental chair with their son in their lap and they would wrap all their extremities around the child – arms and legs – in order to keep the child still for dental care. Although some parents laughed about this acrobatic use of their bodies, there was general consensus that it was a stressful process. For example, one mother explained that

...usually when we take him [her son] to the dentist it has to be both my husband and I because, really, it's so rough on us we have to take turns...I think we both get very nervous, it's a very tense experience for both of because, and, um, usually I restrain, but sometimes I rely a lot more on my husband to be there restraining him, but sometimes it takes both my husband and I and the dentist, just, you know, um, to hold him down because he will try to pry himself off no matter what.

However, multiple parents also mentioned that as their sons got older, the mothers were unable to restrain them anymore; "...for me, I had to hold our son, and then my husband had to hold him because he is so tall and I can't hold him anymore". Additionally, parents were unsure as to the future when parental restraint was no longer a possibility, as highlighted by this mother's statement, "...he is almost as tall as me, so it's hard, I mean, you know, I can't physically restrain him anymore, so, uh, we'll see how that goes..."

Although these experiences were stressful for both children and parents, parents conveyed a greater acceptance of their personal use of restraint for their child, compared to how they expressed their experiences of dental staff utilizing protective stabilization techniques. For example, one mother recalled how she and her husband saw her son kicking and screaming through a window in the dental room door "...and my husband was going to go in there and beat somebody up it was that bad. Cause it looked like they were torturing him, so it was tough on him, and it was really tough on us..." Another father explained that when he heard his son

...screaming for me from front...I went in there, and there was, like, several people trying to restrain him. They had him in restraints and my wife was in tears.

Obviously, when I walked into the room everyone that worked there kinda backed away because they thought I was going to do something because daddy is finally here...because of that, that experience, we were extremely hesitant to take him back.

Multiple parents also reported that it was common for multiple staff members to be needed to restrain their child for treatment, often using a papoose board. As one mother explained about her son's first dental visit, "...he just freaked out. So it took, like, seven adults to, try to, you know [restrain him], and I had to sign a consent to wrap him up..."

In contrast, one mother explained to the group that she was worried about her current dentist because "...she doesn't have the equipment. Though she's really nice, she doesn't have the equipment or the manpower to strap him down, so, like, going in the future, you know, this is not gonna work." This mother believed that the use of professional restraint was essential to provide safe and effective care to her son, and was concerned that her dentist was not going to be able to provide it in the future as he grew bigger with age.

Drugs: "It's a Mixed Bag"

The use of pharmacological methods was reported by parents to have both negative and positive attributes. For example, multiple parents stated that the use of nitrous oxide (laughing gas) did not work well for their child. One mother explained how her son

...does not respond well to nitrous oxide. In fact, it makes him aggressive; he was screaming, he was kicking, despite having a lot of nitrous oxide...it just did not work. He was fully alert throughout the whole thing...we spoke to our new dentist [about the lack of success with this technique], she agreed, she said, this is per her, she said that the research is showing that there is [sic] a lot of autistic kids that don't respond to that, so I guess my son is one of those, so that's not going to be an option for us anymore.

In contrast, other parents reported that the use of nitrous oxide was very helpful for avoiding and alleviating difficult dental experiences. As one mother explained, her dentist says that

...as soon as there is any significant problem it's off to the nitrous oxide room. No problem at all; kids love it! So, he [the dentist] just doesn't want it to be a traumatic experience at all. So he says that if there's any trauma then we'll gas up and we're done. So we're very happy that he is so, I don't know what you call it...so much 'intervention'.

In regard to the use of general anesthesia, multiple parents explained that the experience was initially scary for them. For example, one father explained that he didn't want to leave the room after his son was put under anesthesia, stating that "...it was a rough two and a half hours, it felt like weeks, you know, waiting in that waiting room. Um, I smoke, so I inhaled that pack, I mean, I was so scared." He also described how it was initially scary when his son was "coming out of it and kinda shivering, which you don't want to see your kid [like that]. I thought he was in pain, but he was just out if it, trying to wake up." However, that same father described that, despite the fear, it was worth it to have his son "put under" because the needed work was able to be completed successfully and without incident. Another mother echoed these sentiments, but had chosen general anesthesia for her son because nitrous oxide didn't work with him either. In her opinion,

...it's far easier to take him in and, you know, have him get general anesthesia and then when he's out he's out, it's like he doesn't have to fight through it, he doesn't have to be aware of what's going on. It's been easier so if that's the way it's going to work for a dental visit; I'm not a proponent of general anesthesia, that's scary and I know it carries risks, but I don't care, it's just so much easier because we've gone through really traumatic experiences at the dentist...

Ultimately, parents agreed that the use of pharmacological methods, when successfully implemented, made dental visits easier and less traumatic for their children. One mother explained that she felt the use of drugs were positive because "there's that whole emotional thing that you can't discount", describing how with drugs there's no upsetting memory of treatment at the dental office. In fact, in one of the two focus groups, parents began a conversation about possible over-the-counter pharmacologic choices that were "safe methods to make him fall asleep" (e.g., Benadryl) in order to make the dental experience easier for the child.

Discussion

These qualitative findings are among the first to give voice to challenges caregivers face related to oral care for their children who have ASD. These findings confirm our previously published survey results (Stein et al., 2012) in that parents unanimously identified and described experiencing difficulties with regard to access to professional dental care for their children. This is supported by other survey studies which indicate that parents encounter challenges finding a dentist with the skills or willingness to work with their child with autism (Brickhouse et al., 2009) and that approximately 60–68% of general dentists reported that they do not treat children with ASD (Dao et al., 2005; Weil & Inglehardt, 2010). The main contribution of this study's findings, however, is capturing how these challenges are experienced, explicating that it is not solely a problem finding a dentist, but rather difficulties with dentist rejection, dentist misrepresentation, referrals, and cost.

Dentist rejection and misrepresentation may be related to dental education, as 58% of parental survey respondents reported that the dentist stated that he/she did not have adequate dental training to treat their child with ASD (Stein et al., 2012). This is supported by a study that found that general dentists agreed that the more their dental education had prepared them to work with people with special health care needs, the more likely they were to treat patients with special needs and the more they liked treating these patients (Dao et al., 2005). A similar study found that pediatric dentists, who have had more didactic and hands-on training with children with special needs, treat significantly more patients with ASD as compared to general dentists (Weil & Inglehart, 2010). In regard to difficulties finding a dentist and referrals, the American Academy of Pediatric Dentistry (AAPD) has recently published a policy on the *dental home* for all infants, children, adolescents, and individuals with special health care needs (AAPD, 2014–15a). In this model, referral from a primary care physician or other health provider to establish a dental home is recommended to occur no later than 12 months of age, with children in a dental home more likely to receive appropriate and needed preventive and routine oral health care (AAPD, 14–15). However, as suggested by our findings, the usefulness of that referral may hinge on rapport, trust, and the existing relationship between the patient family and physician. Additionally, collaboration with online Autism parent groups to publish locations for appropriate dental care for their child, such as that on Autism Speaks webpage (2015a), may be a useful strategy as multiple parents in our focus groups mentioned online research as a commonly utilized tool to identify potential sites for dental care. Lastly, available resources such as Autism Speaks's Dental Toolkit and Dental Guide (2015b) and the Autism Speaks/Autism Treatment Network Dental Professional's Toolkit (2015) may be useful to both parents and dental providers as a way to assist the entire dental process, from finding the right dentist to effectively preparing for dental appointments (e.g., recognizing that all children with ASD are unique and therefore require individualized accommodations, and communicating child-specific needs to the dental professional prior to care).

The qualitative findings from this study also illustrate that sensory sensitivities are particularly challenging as they may be present throughout all sensory modalities during dental care. This expanded upon our previous quantitative findings (Stein et al., 2012) and is not surprising as reports indicate that up to 95% of children with ASD exhibit some form of

sensory processing difficulties (Ben-Sasson et al., 2009; Tomchek & Dunn, 2007). In the dental literature, multiple articles discuss the possible negative impact of sensory processing difficulties on dental care experiences in children with ASD (Barry et al., 2014; Friedlander et al., 2003; Green & Flanagan, 2008; NIDCR, 2009). Recent empirical research has supported this link between sensory processing and dental care difficulties in children with ASD (Stein et al., 2011; Stein et al., 2013; Stein et al., 2014). Likewise, sensory challenges have been reported to occur in other healthcare environments, such as the hospital (Davignon et al., 2014; Muskat et al., 2014), primary care (Pfeiffer & Stein, 2016), and the emergency room (Giarelli et al., 2014). If dental professionals are aware of and understand the potential impact of sensory sensitivities on children with ASD, there are many adaptations that can be made to help the child and their family feel more comfortable with care. For example, a recent study sought to adapt the sensory features of the dental environment, suggesting preliminary support for the success of these environmental changes in decreasing negative reactions at the dentist (Cermak et al., 2015). Additionally, disseminating and discussing the implementation of practical guides for dental professionals working with children with ASD, as done by the National Institute of Dental and Craniofacial Research (2009) for oral care or for medical professionals working with individuals with ASD in the emergency room (CARD, n.d.) could benefit this population greatly.

Surprisingly, parents participating in the focus groups didn't speak directly about their child's uncooperative behavior; instead, they spoke of the techniques used to treat that behavior, specifically the use of restraint and pharmacological methods. Both protective stabilization, which restricts a patient's freedom of movement (utilizing the dentist, staff, parent or restrictive device) in order to provide safe and effective care, and general anesthesia are advanced behavior guidance techniques taught in advanced training and used for children who "cannot cooperate due to lack of psychological or emotional maturity and/or mental, physical, or medical disability" (AAPD, 2014–15b: 184). Children with ASD are a heterogeneous group with diverse levels of functioning. Some may have the ability to cooperate with dental treatment with only basic behavioral guidance techniques (Friedlander, 2005; Loo et al., 2009), especially when the dental professional has special expertise and extra time. However, for children with ASD exhibiting uncooperative behaviors, dental care may be nearly impossible to perform without the assistance of advanced behavior techniques such as restraint or pharmacologic methods.

Similar to the findings of our survey (Stein et al., 2012), Loo et al. (2009) found that protective stabilization was used during 20% of dental treatments for children with ASD, significantly greater than that used for typically developing children (0%) and that the use of protective stabilization (dental professionals, caregiver/parent, restrictive device, or a combination of these techniques) was the second most commonly utilized advanced behavior guidance technique used for children with ASD. Parents in the focus group tended to be more negative when describing protective stabilization utilized by dental professionals (vs. parents using restraint), similar to another study whose parent survey respondents expressed that parental restraint was more "acceptable" than staff restraint (Marshall et al., 2008). In that study, parents also believed that their personal use of restraint was more efficacious as compared to staff restraint (Marshall et al., 2008), a sentiment not mentioned

in our focus group discussions. In contrast, in a study by Lewis et al. (2015), some parents reported a preference for relying on professionals to provide restraint for children during dental care in lieu of parental restraint. Some dental literature has reported anecdotally that the use of a papoose board can have a calming effect on children with ASD during dental care (Marshall et al., 2008; Ravel, 2005), based on the work of Temple Grandin (Edelson et al., 1999; Grandin, 2006). Similarly, recent research suggests that the use of a chair wrap designed to provide deep “hugging” pressure has the potential to produce a calming effect in children with ASD when used in conjunction with visual and auditory environmental adaptations (Cermak et al., 2015).

A diagnosis of ASD is one of the most frequent profile traits for utilization of advanced behavioral strategies such as general anesthesia (Hulland & Sigal, 2000) and has been reported to be utilized from 18% (Marshall et al., 2008) to 37% (Loo et al., 2009; Stein et al., 2012). However, general anesthesia can be dangerous due to adverse drug interactions (Friedlander et al., 2003), potential injury to the child’s developing brain (Smart Tots, 2015), and its high cost may be prohibitive for un-insured or under-insured families, which can impact frequency of dental prophylaxis (Marshall et al., 2008). Parents in our focus groups were torn as to the merits and draw-backs of the utilization of this type of technique. As pointed out in the focus groups, the ability to provide highly effective care without the risk of traumatic experiences or memories of dental care made this type of treatment choice worth the associated risks and cost of pharmacological methods, a sentiment also supported by some parents of children with ASD participating in Lewis et al.’s (2015) study. Interestingly, in a previous survey the majority of parents of children with ASD also reported that the use of general anesthesia was acceptable and worked well for their child (Marshall et al., 2008).

Ultimately, in addition to increasing access to care for this population, the importance of dental interventions that utilize the least restrictive behavior techniques and/or take into account the unique sensory experiences of this group is paramount. Flexibility and creativity are essential in the dental office, as simultaneous use of multiple accommodations may benefit children with special needs, especially those with ASD (Weil et al., 2011). 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 (Weil et al., 2011). As mentioned earlier, a recent study adapted the visual, auditory, and tactile environment of the dental operatory during routine dental cleanings, successfully decreasing the physiological distress, behavioral distress, perception of pain, and sensory discomfort in children with ASD (Cermak et al., 2015). Additionally, another recent study found that electronic screen media technology utilizing video goggles significantly reduced children’s anxiety and behavior scores during dental cleanings (Isong et al., 2014).

In our study, parents of children with ASD reported both positive and negative experiences with advanced behavioral interventions, which makes it difficult to discern what comprises best practices to families. However, clear communication between the dentist, parent, and patient (when able) is essential. As parental anxiety has the potential to negatively influence child behavior during dental care, communication is especially important between dental

professionals and parents when behavior guidance options are chosen and carried out (AAPD, 2014–15b). For example, the horrified descriptions of restraint from the parents in our study underscore the importance of communication between professionals and parents.

Although these findings highlight and help us better understand important challenges in the dental care experiences of children with ASD, several limitations must be noted. First, inclusion in the ASD group was based solely on parent-report; no gold-standard confirmation utilizing diagnostic tools was conducted. Additionally, no formal assessments were conducted regarding the level of functioning of the participants' children. However, we did collect information regarding the children's highest level of communication ability, which provides some insight as previous research suggests that children with ASD's ability to talk is significantly and positively correlated with the child's dental health as well as parents' comfort taking the child to the dentist (Weil & Inglehart, 2012). Second, because our study was conducted in the Southern California area and included only two focus groups, our sample may be at risk for self-selection bias; therefore, results cannot be viewed as representative of all parents of children with ASD. Although saturation in focus groups can often be achieved through as few as four-five groups, this study only conducted two. Nevertheless, the findings help us to better understand the experiences of parents of children with ASD, which can be used to improve patient care or inform new interventions to improve patient care. Third, all the parent focus group participants had sons with autism. Although there is a gender bias in ASD diagnosis, with a 5:1 male-to-female ratio (CDC, 2016), the experience of parents of girls with ASD may be different and is not represented here. Last, this study reports the experiences and opinions of parents of children with ASD which may differ from the perceptions of individuals with ASD themselves.

Conclusion

The dental care experiences of families of children with ASD as well as the dental professionals that treat this population are essential to ultimately determine best practices to improve access and develop interventions. By better understanding the obstacles to dental care this population faces, dentists and other health care providers can work to minimize the difficulties encountered by children with ASD. In this study, parent participants provided extensive information when describing their child's dental care experiences. Utilizing this information to provide care and alleviate some of the challenges experienced by this population has the potential to improve care greatly, similar to that suggested by Lewis et al. (2015). This insight may help professionals identify priorities for planning efforts to address the oral health-related needs of this population, design new methods and procedures to best serve children with ASD, and develop collaborations between dental professionals and other practitioners who commonly work with these children (e.g., occupational therapists, psychologists, behavioral therapists).

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HIGHLIGHTS

- Parents report that receiving oral care in the dental office is challenging for children with ASD.
- Challenges include access to care, sensory sensitivities, and the use of restraint and drugs.
- By understanding the dental care experiences of families of children with ASD, health care professionals can work to improve access to and accommodations for care.

Table 1

Focus Group Participant Characteristics

Descriptive Characteristics		Focus Group Participants (n=9 Parents)
		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 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)
	Highest level of child communication:	
	Gestures	1 (11.1)
	Single words or phrases	3 (33.3)
	Sentences	5 (55.6)
	My child is unable to communicate	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)