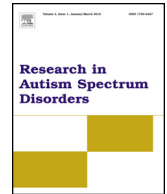




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Parents' perceptions of dental care challenges in male children with autism spectrum disorder: An initial qualitative exploration



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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".

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.

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1. 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

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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, Robertson, & Phelps, 2005). The majority of research indicates that children with ASD exhibit a high prevalence of poor oral health, as measured by prevalence and severity of caries (DeMattei, Cuvo, & Maurizio, 2007; Jaber, 2011; Kopycka-Kedzierawski & Auinger, 2008; Marshall, Sheller, & Mancl, 2010), despite a small number of contradictory studies (Fahlvik-Planefeldt & Herrstrom, 2001; Loo, Graham, & Hughes, 2008; Morinushi, Ueda, & Tanaka, 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, Farrington, Best, & Ellsworth, 2009; Weil & Inglehart, 2010), impairments in child communication (Marshall, Sheller, & Williams, 2007), uncooperative behaviors (Brickhouse et al., 2009; Loo et al., 2008), difficulties with sensory processing (Stein, Polido, Mailloux, Coleman, & Cermak, 2011; Stein, Polido, Najera, & Cermak, 2012; Stein, Polido, & Cermak, 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.

2. 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.

2.1. 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.

2.2. Data collection

The two focus groups were semi-structured and utilized the cornerstones to focus group success as outlined by Coté-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

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