

Oral Care Experiences of Young Adults with Autism Spectrum Disorder

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Abstract

Purpose: Individuals with autism need oral health care providers who understand their sensitivities and are responsive to their oral health care needs. The purpose of this study was to understand the oral health care experiences and needs of young adults with autism spectrum disorder (ASD).

Methods: A qualitative descriptive research design was used and young adults with ASD were recruited through purposive and snowball sampling. Semi-structured interviews with open-ended questions were conducted and audio-recorded. Pseudonyms were used to protect confidentiality. Interviews were transcribed and data were analyzed simultaneously at the time of data collection. Open coding and axial coding were used to create common categories. Validity was established using investigator triangulation and member checks.

Results: Fifteen individuals (ten males and five females) met the inclusion criteria and participated in the study. Participants revealed a range of feelings related to their oral care experiences from positive to neutral to negative. Participants identified likes and dislikes in regard to dental hygiene and dental treatment as well as daily self-care practices. Individuals reported that improvements in communication were needed; some indicated not wanting to disclose their ASD diagnosis with their oral care providers. Multiple auditory, visual, and tactile sensory challenges were experienced while waiting in the reception area and during the provision of oral health care treatment. Participants made recommendations to improve oral health care experiences.

Conclusions: Results from this study offered insight into the oral care experiences of young adults with ASD and the challenges they encounter. Additional research is needed to further explore this phenomenon from the perspective of non-verbal individuals with ASD and from the standpoint of oral health care professionals who are working with young adults with developmental disabilities.

Keywords: autism spectrum disorder, young adults, oral care, dental hygiene care, access to care, perceptions, qualitative research

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Introduction

Over the last 30 to 40 years the number of diagnosed autism cases has been rising globally, as well as in the US.¹ This increase in occurrence is thought to be a result of better diagnostic practices using broadened diagnostic criteria and children being identified at younger ages.¹⁻³ Another factor is increased parent awareness; in many cases the cause of autism is linked to genetics and the tendency it has to run in families.^{4,5} In 2018, the Centers for Disease Control and Prevention Autism and Developmental Disabilities Monitoring Network reported the prevalence of autism was 1 in 59 children over the previously reported 1 in 68.² The predominance continues to be 5 times higher in males than

females.² As the reported incidence of autism rises, individuals with autism will need to find oral health care providers who understand their sensitivities and are responsive to their oral health care needs.

In the fifth edition of its *Diagnostic and Statistical Manual (DSM-5)*, published in 2013, the American Psychiatric Association (APA) described autism as having previously been represented by four individual diagnoses consisting of autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger's syndrome.⁴ In 2013, the APA merged these four categories into one diagnostic term of autism spectrum

disorder (ASD). Autism spectrum disorder is a persistent neurodevelopmental disorder with an early onset beginning in childhood and developmental delays appearing as early as 18 months or even younger. Most diagnoses are established between year 2 and 3 and last throughout life.⁶

Individuals with ASD often appear physically normal, yet generally lack socialization abilities.⁶ They frequently have difficulty with communication including an inability to initiate or continue conversations or to answer questions.⁴ Additionally, individuals with ASD may misunderstand jokes, sarcasm, or teasing.⁶ They generally speak in flat, robot-like, or sing-song speech.⁶ Also characteristic are social issues of avoiding eye-contact and resisting physical contact, extreme reaction to invasion of personal space, and unusual sensory interests or sensitivities.^{4,6}

Individuals with ASD experience challenges within the course of their daily lives; however, oral care involves extreme sensations associated with visual, auditory, tactile, olfactory, or gustatory stimuli.⁷ Studies have shown that individuals with ASD have behaviors that put them at higher risk for oral diseases.⁸⁻¹¹ These behavioral impairments include difficulty with communication, impaired social interactions, restricted interests and eating habits, resistance to oral care, and repetitive and stereotyped behaviors.⁴ Even though many individuals with ASD have dental visits, many do not receive the level of care essential to maintain good oral health.¹²

Investigations have studied sensory processing issues, communication techniques, and behavioral management for children with ASD when faced with oral health care visits.¹³⁻¹⁵ Glaring fluorescent lights, moving back in the chair, touching in the mouth especially the tongue, and tasting and smelling oral care products are regular sensory characteristics of the oral health care visit, however these stimuli can trigger children with ASD to react with anxiety and uncooperative behaviors.¹⁵ Consequently, the simple behavior guidance techniques such as tell-show-do, distraction, positive reinforcement, and voice control, as well as relationship building strategies that are successful with typically developing individuals, may not be successful for individuals with ASD.^{13,16,17} Non-traditional methods of behavior guidance, such as book-based visual pedagogy,¹⁸ social stories, video modeling and desensitization¹⁶ have had greater effectiveness for individuals with ASD than traditional approaches alone.

In one study, sensory processing techniques were proposed as strategies to mitigate obnoxious sensations for children and young adults with ASD during oral health care visits.¹⁹ In another study researchers addressed desensitizing the environment to achieve a similar effect, of lessening

anxiety and decreasing uncooperative behaviors exhibited by individuals with ASD in the oral health care setting.²⁰ Oral health care providers need to be aware of the many stimuli that occur during oral health care visits and be prepared to make individualized adaptations for each patient.^{19,20}

Recommendations to diminish sensory stimuli for patients with ASD in oral health care settings include: verbally preparing the patient by describing what will take place to prevent startling them and offering alternative products with tastes and smells consistent with patient preferences. Other techniques include using firm deep touch rather than light touch and making as little contact as possible with the face and tongue, avoiding direct eye contact, wearing transparent face shields, and blocking as much light as possible by providing sunglasses and dimming the overhead lights.^{21,22}

Research to date has largely been conducted from the oral health care providers' and parents' perspective. No original primary research has been reported in the literature related to young adults with ASD and their oral care experiences. There is also a need to determine whether the oral health needs of children with ASD are the same as the oral health care needs of young adults with ASD. The purpose of this qualitative study was to better understand the oral health care experiences and needs of young adults with ASD.

Methods

This study was reviewed by the University of Idaho's Human Subjects Committee and received Institutional Review Board approval (IRB-FY2020-117). A qualitative descriptive approach was used to facilitate an in-depth exploration of the oral health experiences and needs of individuals with ASD. This qualitative study design has been shown to be appropriate when exploring phenomena where little theoretical or practical knowledge exists.²³

Purposive sampling, as used in this study, is often utilized as the sampling procedure for a descriptive qualitative study.²³ Participants were initially recruited through personal networking by the principal investigator (PI) posting a brochure at a non-profit human service organization serving communities with special needs in southeast Alaska. The snowball sampling was then used to gain referrals of other individuals with ASD who could be recruited for the study.^{24, 25} Inclusion criteria consisted of young adults diagnosed with ASD between the ages of 18 and 35, who were able to communicate verbally in English, who were willing to participate for up to an hour of interview questioning, and who had an oral healthcare visit within the last two years. Preference was given to participants who had not been patients in the PI's dental practice setting

to promote maximum variation and decrease bias. A screening questionnaire was completed to verify that inclusion criteria were met. The questionnaire included demographic information, living arrangements, type of ASD diagnosis, identification of the consent form signer, date of last oral health care visit, and preferred pseudonym. The forms indicating informed consent to participate in the study were explained to potential participants and/or parent/guardians by the PI.

Six research questions directed the development of the interview guide. These research questions focused on interviewees' experiences related to oral health care visits; their likes/dislikes of techniques used by oral health care providers in the delivery of oral health care; their experiences of communication techniques provided by oral health care providers; their likes/dislikes related to oral self-care recommendations; the challenges they have encountered when seeking oral health care; and their recommendations to improve their oral health care experiences. The interview guide and consent form were developed with an individual who had early childhood development and special needs expertise. This guidance help ensure that participants would understand the consent form and interview questions.

A series of in-depth, semi-structured interviews utilizing open-ended questioning was conducted by the PI to gain richly descriptive data.^{25,26} Interviews were conducted either in a private room, by telephone, or over an Internet video conferencing platform (Zoom; San Jose, CA) to maintain anonymity and minimize sensory distractions. The interview questions were pilot-tested with one individual with ASD following the study's protocol for data collection to verify participant understanding of the questions. Interview questions were distributed in advance of the scheduled interviews. Interviews were audio recorded. Participant pseudonyms were utilized during the interviews and on the transcript to protect confidentiality and ensure anonymity. Each interview was transcribed directly following the session; the PI listened to the audio-recording to verify the transcriptions were accurate.

Data regarding the oral health care experiences of young adults who have ASD were analyzed simultaneously with data collection.²⁵ After the first interview was completed the transcript was reviewed by the co-investigators and compared to the research questions to ensure the data were aligned with the purpose of the study, and then used to guide the next interview. Data analysis began with open coding, a procedure to deconstruct the data into words or brief phrases representing the participants' experiences relevant to answering the research questions.²⁵ As open coding of multiple interviews was completed, similar open codes

emerged from the analysis. During axial coding, open codes were grouped together to create a common category which provided an interpretation of the meaning of the data.²⁵ Each researcher coded the same interview and discussed findings until consensus was reached.

Validity was established through investigator triangulation with the three investigators individually evaluating data separately and finding comparable results.²⁵ Respondent validation occurred in which a summary of the transcript was offered to each interviewee for review as part of the peer debriefing process to aid in establishing the accuracy and validity of the qualitative data.²⁵ Lastly, 11 of 15 participants performed member checks, evaluating the preliminary findings and verified the accuracy of the researchers' interpretation of the data. These participants confirmed responses to support data analysis. Four participants chose not to respond. Demographic data were analyzed using descriptive statistics. Frequencies and percentages were used to report information for the fifteen participants.

Results

Data saturation was achieved after fifteen interviews. No new categories were identified to answer the research questions.²⁵ A total of 15 individuals, ten males and five females, participated in this study. Ages of the participants ranged from 18 to 35 years; the average age of the interviewees was 25 years. Participants resided in eight states from the Northwestern region of the United States. Twelve (80%) lived at home while three (20%) had independent living arrangements. Participants' descriptions of their own ASD were based on diagnoses received before the publication of the DSM-5. Three (20%) described themselves as having autistic disorder, 3 (20%) described themselves as having pervasive developmental disorder-not otherwise specified (PDD-NOS) and 9 (60%) described themselves having Asperger's Syndrome. The following results are presented in relation to the major research questions of the study.

Experiences Related to Oral Care Visits

Participants were asked to describe their own experiences related to oral health care visits. A range of responses were provided which demonstrated a continuum of emotions in three categories, ranging from feelings that were positive to neutral to negative. For instance, Link described being happy stating, "Because I know I can take care of myself. I know when they get done with your teeth, I feel happy." An example of a neutral expression was reported by Evans, "I feel, to be honest, pretty neutral when I go. It's like another thing in my life to do." On the other hand, Rose had a more

negative response to her visits and shared, “I don’t know if they’re going to hurt me or if they’re not going to hurt me and I have to play it in my head that nothing’s going to happen, but there’s always that fear that’s there.”

Participants were asked to describe how they felt when they encountered a different oral health care provider than the person they were used to seeing. Responses included cautious, apprehensive, inconvenienced, and agreeable. Additional key quotes representing these emotions are shown in Table I.

Table I. Emotional experiences related to oral health care visits

Positive emotions or feelings
“I’m pretty happy when I visit there. There’s a slight bit of nervousness, but it’s nothing to make me panic or anything like that. I’m generally calm. I’m still pretty happy when I visit the hygienist, but the only difference is that there’s zero nervousness when it comes to dental hygienists. That’s way more relaxed. I was a weird kid. I loved the dentist. I’m generally very calm, very happy going.” (Kevin)
Neutral emotions or feelings
“I feel all right. I just feel like it’s what has to be done. They’re just checking me out, not doing anything bad. And so I just follow it. Because I can’t do this by myself. I’m sure my teeth are okay but there’s always professionals doing it, making sure I don’t get cavities and they point out what I may need some help with.” (Elaine)
Negative emotions or feelings
“I’m usually really scared and then that turns into anger. I get mad after being in the situation for a little while, but at first I’m just scared. It’s a situation where I’ve had a lot of negative experiences in the past, and I don’t really have a lot of trust for dentists because there’s really poor communication there, even when I try to make it clear what my needs are. Then if that’s just reinforced then I get angry when I don’t feel like I have any control in the situation.” (Sophia)
Feelings towards a different oral health care provider
“It’s easier for me especially getting a new person the second time. Once I know them after the first time I know what to expect. The second time is easier than the first time. It’s less anxiety for me. The one thing I don’t like is when they keep switching people on me. I like to keep the same person.” (Polar Express)

Likes and Dislikes Related to Oral Health Care Delivery

Study participants were asked to identify what they liked or disliked about strategies dentists and dental hygienists used to improve oral health care delivery. A variety of responses were provided. For example, Evans stated, “The fact that they treat me like I’m a person and not like a patient,”

while Bob reported, “Well, if my teeth were clean, I like the compliments that I receive, and the general, amicable atmosphere afterwards.” Journey Boy enjoyed “getting a toothbrush,” but indicated that “it’s just painful and I don’t like them picking around in my teeth; if they’re poking in my mouth, it hurts.” Some participants were uncomfortable getting injections or found other procedures unpleasant, while others were apprehensive of the anticipation of an experience. Sophia explained her concern:

“In the moment I’m just thinking, okay when the dentist comes I have no idea what they’re going to do. The part I hate the most is not when the dentist comes, it’s everything before that, not knowing what’s going to happen.”

Table II provides supplementary key quotes expanding on the categories of likes and dislikes about dental and dental hygiene treatment approaches.

Table II. Participant feelings towards oral health care treatments/providers

Dental hygiene care	
Liked	Disliked
“The thing I like the most is that once it’s done your teeth are clean and you know what you’re supposed to do to improve if you’ve been lacking in a certain area. Also, the people there are always nice. They give you a bag of stuff. I remember one time I got this tongue scrubber thing that you put on your tongue and it removed debris from your tongue.” (Ethan)	“Those scrapers, those small metal hooks that scrape the teeth for any plaque. It kind of gives me goosebumps, if it gets to a bad area almost close to my gums, so that’s why I have to use my tongue to make sure it doesn’t get there. I don’t think I could say I dislike it. I just don’t want a scraper hurting me.” (Elaine)
Dental treatment	
Liked	Disliked
“My dentist that I go to is really kind. He really knows how to take care of me and make me feel comfortable. He does give me support and encouragement to keep up the good work on my brushing. I like him. I just like his smile. He has a pretty jovial attitude. He’s very kind, very friendly and the people that work with him are very nice as well.” (Quinn)	“I don’t like the shots. And the weird sounds of the instruments they use. I don’t like that at all. When they take molds of my mouth. It feels like there is something foreign in my mouth. It’s a really uncomfortable feeling, so it just makes my anxiety goes up when they do those types of things.” (Rose)

Communication Techniques

Communication was a phenomenon explored with the participants. Categories of communication that emerged from the data analysis included positive and negative verbal experiences, positive and negative nonverbal experiences, and communicating ASD diagnosis. David provided an example of a positive verbal communication experience, stating that “a good hygienist anticipates your needs.” Participants encountered negative communication at times. Bob reported “If I didn’t do a good job cleaning my teeth, [I would be] scolded by the dentist or dental hygienist afterwards.” Additional examples of communication experiences, including non-verbal representations, are provided in Table III.

When discussing communication issues, participants also discussed whether or not they disclosed their ASD diagnosis with their oral health care providers. The PI pursued further questioning asking participants if they would want their provider to know more about their condition. For example, Rose explained:

“No, only because I don’t want to be looked at as more different than any other patient that comes through. So, I don’t really disclose anything that could be traumatic or could have myself looked in a different way than anybody else in there.”

However, Quinn felt differently, expressing:

“I would rather they did know, mostly because they want to be able to get more experience on working with people like me so they’ll know how to treat others that have autism, PDD-NOS and other symptoms such as that.”

Finally, Polar Express stated:

“I think it’s something people should be trained to identify. They should treat everybody the same; treat everybody like they might have spectrum. Just have the sense of caring. They shouldn’t treat anybody any different just because you have autism.”

Table III. Participant responses to communication practices

Positive communication experiences
<p>“Their attitude, they’re very nice, and then they make me relaxed. They say, are you comfortable in your chair? I’m like, all right. And also they’re like, Hey, you need to spit, when they filling your mouth up with whatever they are filling it up with. They make me relaxed and comfortable because they know it’s kind of a long and thorough process for them to clean your teeth.” (David)</p> <p>“I talk to them like they’re another person. Usually, I’m not really the best at starting conversations. They meet me, they welcome me. We have a little conversation. Like, how are you doing? Hi, how’s your day been? And then we get into the process of cleaning up our teeth. Maybe if I don’t feel comfortable with something they’re doing within my mouth, I’ll make a noise or I’ll ask for something, they’ll usually provide it. If something feels painful, they’ll try and lighten it a bit, so that there’s not as much pressure being put on it, so that it doesn’t hurt as much.” (Evans)</p>
Negative communication experiences
<p>“It’s just once a rapport is established, I think more conversation can occur. But on the initial, I would say alleviating that stress of a new experience is probably the most productive thing someone can do. Experiencing something new with autism is far more stressful than other people. I actually have physiological panic attacks. My heart rate would go up, my blood pressure will increase. I release adrenaline and I actually... if it culminates, I will have a panic attack where I will have to escape or I will become strangely violent potentially, but that it takes a lot of duress for that to culminate.” (Karl)</p>
Positive non-verbal communication
<p>“My current dentist, who I’ve seen a couple times, I really like. She’s the only one I’ve ever met who takes the conversations that happen behind you and moves them in front of you. She’s talking with the dental hygienist, she’s getting everything ready within my field of vision, and she’s explaining things to me. She’s doing the things that I appreciate about my dental hygienist that I think come from having more time, not being as rushed. I really like when she engages me instead of just opening my mouth and sticking stuff in there.” (Sophia)</p>
Negative non-verbal communication
<p>“I don’t like that I can’t read their faces as well because they have a mask on, or they’re somewhere where I can’t really see their face. That makes it hard, because then I don’t feel like I’m getting any non-verbal communication from them really. In the past they’ve had me do hand signals. Just to tap my stomach if I need to step back for a second. We come up with little codes like that, but that hasn’t always worked out in the past. If we come up with the code, and it seems clear, and then in the past I’ve had dentists not really be onboard with that, even if it’s well communicated. I don’t know maybe they just forget or this takes all of their attention being in my mouth.” (Sophia)</p>
Communicating ASD diagnosis
<p>“No, they don’t know that I have an autism spectrum disorder. I don’t put it on the health history. I don’t want to be treated differently. People treat you weird.” (Polar Express)</p> <p>“Yes, the most recent one [dentist] does. I think it probably would’ve been helpful. Definitely would’ve been helpful in the past if I had the knowledge myself to be able to communicate that to dentists, or try to find one who had a specialty. But unfortunately, I didn’t realize until the past year and a half. But it’s been good information to be able to share since then”. (Sophia)</p> <p>“I don’t really care if they know or if they don’t. I’m pretty sure it’s on my health history. It doesn’t matter to me either way, but to know, because if I act weird, then they’ll know.” (Ray)</p>

The various perspectives regarding self-disclosure of an ASD diagnosis are shown in Table III.

Oral Self-Care Recommendations Likes and Dislikes

Participants were asked to describe what oral self-care recommendations they liked or disliked. Responses were on the continuum of three categories: likes, neutral and dislikes. Participants agreed that they liked to brush; however, many pointed out how they forgot to brush a second time during the day as evidenced by David who stated, “I brush my teeth at least once a day, I know I’m supposed to do it twice a day. I try to do it twice a day. I like the feeling of having a clean mouth.” While Sophia felt differently about brushing explaining,

“I don’t like a toothbrush in my mouth. I don’t like thinking about my mouth. If I draw any attention to it then I’m feeling everything, and it’s really unnerving. It didn’t used to hurt, but now I have bad oral hygiene because now it does hurt to brush my teeth. But mostly it’s just the pressure on my teeth.”

Responses to flossing and other self-care procedures were similarly divided by the participants and are shown in Table IV.

Table IV. Participant attitudes towards oral self-care recommendations

Like
<p>“I have the little tiny toothbrush. It’s a round head. Maybe a third of the size of a regular toothbrush head. It lets me do it more one place at a time, and it lets me clean probably better than a regular toothbrush without it becoming too much of a sensory experience as it normally would. Having that little tiny toothbrush has been a lifesaver. It’s still hard, and so I don’t do it as often as I need to, obviously. But it means I can handle it at all.” (Sophia)</p> <p>“I like doing the floss, because it gets my teeth cleaned. That’s the thing I liked the most and that tongue scraper.” (Ethan)</p> <p>“I use fluoride rinse and some kind of fluoride toothpaste. I put it on my toothbrush and brush my teeth with that twice a week, or at least I try to.” (Bob)</p>
Neutral
<p>“I never liked nor dislike it [daily oral hygiene], I know it’s just something that I have to do.” (David)</p>
Dislikes
<p>“I don’t like how the toothpaste always gets bubbly and fills up my mouth.” (Ethan)</p> <p>“Flossing hurts and I don’t like doing it.” (Rose)</p> <p>“I don’t like mouthwash. I don’t like using it. I don’t like the taste of it, well, except cinnamon. Cinnamon that is the only exception. I do not like using mouthwash at all.” (Kevin)</p> <p>“I do grind my teeth a lot, so we got a mouth guard. I really wish I could use it, because I wake up with little chips all the time, and it would be great if I could use it. But I couldn’t. I couldn’t handle the feeling of it in my mouth.” (Sophia)</p>

Sensory Challenges during Oral Health Care

Another aspect studied related to the sensory challenges participants experienced during oral health care. These experiences could have occurred while waiting in the reception area or during dental and dental hygiene treatment. Types of challenges included auditory, visual and tactile sensory experiences. When waiting in the reception area, Elaine explained the difficulty she senses noting,

“I’ve been to a lot of places where many people are, so I would just stay there and wait and try to at least get some bubble space around me so I wouldn’t get crushed and try to block out some noise to make sure I can at least get some hearing.”

Another example of an auditory sensory challenge was expressed by Karl:

“If there’s multiple people and they’re having two different conversations at once that can be extremely disorienting. When there’s just copious amounts of acoustic linguistic stimuli, I actually experience aphasia, with all that stimuli. If I’m trying to actually absorb it all at once, analyze every single detail, but that’s impossible.”

Tactile sensory challenges were discussed by several participants. Rose indicated that she preferred moderate pressure when being touched stating, “Light [touch] is irritating. I don’t like being touched lightly by anybody. So a pressurized touch is a lot better. It’s more of a soothing feeling than being lightly touched.” Polar Express described how soothing touch was to him especially during a comprehensive head and neck examination. “When they’re doing this, [palpating his neck] the more pressure makes me feel like they’re actually doing the job right.” However Journey Boy felt differently, “I prefer real light pressure. Because it doesn’t hurt as bad.” Additional detailed responses regarding the categories of sensory challenges are listed in Table V.

Recommendations to Improve Oral Health Care Experiences

The last major concept explored with participants concerned recommendations to

Table V. Sensory challenges encountered when seeking oral health care

Auditory
<p>“It’s a fearful feeling of is that sound’s supposed to be making that sound or what instrument are they really using and how are they really using that and is that something that I could be able to cope with during my visit. I also have what they call is an auditory processing disorder. So I hear everything at the same level of sound. So whether it be down the hall or in the room that I’m in, it sounds the same pitch. There’s no drowning any other sounds out.” (Rose)</p> <p>“It’s both [the sound and the feel of all instruments and equipment]. Equally bad, I think it’s hard to separate them but I think it’s more the feeling. The sound of scraping is hard. I’ve tried to wear earplugs in the past, but that made the sound worse because it’s in your head. So you can hear. Headphones would make it worse only because then I wouldn’t know what is going to happen and what is happening because I wouldn’t be able to hear it.” (Sophia)</p> <p>“Pretty much both [the sound and feel of instruments] because sometimes you’ll hear the equipment in the other room and be like, no, I’m glad I’m not that guy. It’s going through my head right now, all the noise. It’s like nails on a chalkboard. You don’t like it, but they’re getting all the plaque and gunk out of your teeth. It’s not a very pleasant sound and it’s not very comfortable, but they got to do what they got to do.” (David)</p>
Visual
<p>“One thing I don’t like is how the light is always really bright. The light up above your head and you always have to close your eyes that is also when they’re working.” (Ethan)</p> <p>“The hardest thing is just the sensory experience with the lights.” (Sophia)</p>
Tactile
<p>“With other autistic people, I imagine they might experience this as well. It’s just being touched skin to skin can be disconcerting because it interrupts your thought process and you’re just trying to get through that experience, but then you’re interrupted by that and it can cause senses of panic.” (Karl)</p> <p>“Inside my mouth, the inside of my cheeks and my gums, it’s like this electric pain. It just makes me want to scream. But I get desensitized to it as it goes along. It’s not something that builds. Some of the things build, the tools that builds but just in general having this brushing inside of my mouth gets better as it goes. Outside it doesn’t. Outside doesn’t bother me too much but my lips and my gums on the inside of my mouth.” (Sophia)</p>

improve their oral health care experiences. Two categories were identified: recommendations for oral health professionals and recommendations for individuals with ASD. Bob suggested that the oral care provider “keep their questions or comments until after they’re done with the procedure so that I could talk to them directly and have a conversation.” Karl was concerned that the provider ensure that the patient has “a positive experience the first time. It’ll make coming back easier, and then it actually becomes a routine.” Rose offered, “I’ve never been put in situations where other people had to accommodate me. I’ve always had to adapt to my surroundings. I could be more verbal about everything that I have going on.” Additional recommendations for oral health care professionals as well to individuals with ASD regarding ways to improve oral health care experiences are shown in Table VI.

Table VI. Recommendations for oral health care providers and other individuals with ASD

Oral health care providers
<p>“Just maintain that professional tactfulness when it comes to touch. Initial impressions are really important for people with autism spectrum disorder.” (Karl)</p> <p>“I’d meet the dentist and the hygienist at the same time, briefly, and then have the dentist leave. They’d only be there for a second, but at least be there, we’ve exchanged words before they come in for the second time so that there’s some layer of trust there. Kind of what to expect and they might know more what to expect, because I can be clear about my situation. But then not stay too long, because I am really afraid of dentists and then just talk to the dental hygienist for the rest of it.” (Sophia)</p> <p>“Probably letting me know the steps as a process going between each step. Now I’m going to do this, and then complete that step and then move on to the next one and let me know what’s going on as we go through the process.” (Rose)</p> <p>“The smell can be a little bit unusual. So, I would have scents like... more pleasant scents in the office, like a sweet lavender smell; and it would also help to calm someone down, especially if they’re a little less comfortable around being in the dentist’s office.” (Quinn)</p>
Other patients with ASD
<p>“I do deep breathing exercises. Just breathe through my nose, out my mouth. Going to a happy place mindset also helps.” (Kevin)</p> <p>“I have this medicine that I use called Lorazepam, and if anyone else has a prescription for it, I would recommend them taking one before they go to the dentist or the hygienist, if they need it, of course. It calms you down. It’s an anti-anxiety medicine. You take it as needed. It’s never like on a day to day basis, because it’s addictive.” (Bob)</p> <p>“Sit in my car for a while and calm down beforehand. I didn’t stay in the waiting room. They just got me from just outside the door, and then I went straight in. I avoid the waiting room as long as I can wait outside, or in a bathroom or something.” (Sophia)</p>

Discussion

Providing an opportunity for the voices of individuals with ASD to be heard revealed unique discoveries regarding their oral care experiences. First, while some participants felt comfortable reporting their ASD diagnosis to their oral care provider, many indicated they chose not to disclose that information. Having dealt with the stigma of being “different,” they were reluctant to be judged further by someone in health care and preferred to remain silent. Participants shared stories of being made fun of or thought of as weird and did not want to repeat that experience in the dental office setting. For these reasons, they chose not to disclose their ASD diagnosis in their medical history. Huws and Jones²⁷ described how the autism label can be associated with several forms of stigmatizing including enacted stigma or actual prejudice and experiences of discrimination, or felt stigma, in which a person has a perceived fear of prejudice or discrimination whether or not such actions actually occur. Their study of individuals with autism indicated that the boundaries between felt and enacted stigma can become blurred.²⁷

Considering the disclosure of an ASD diagnosis as part of the assessment process, the researcher team examined the American Dental Association (ADA) Health History Form, a standard form available for dental practice settings.²⁸ No category is given for ASD or any other developmental disorders. “Mental health disorders” is listed on the form, but individuals with ASD might not consider themselves to have a mental health issue. The only other item on the ADA health history that might be applicable is: “Do you have any disease, condition, or problem not listed above that you think I should know about?” A recommendation would be to add the category “Developmental Disorders” to health history forms and list several examples including ASD. Electronic health history forms can be customized as can paper forms to include contemporary information such as ASD, making it easier for patients to provide information that would allow providers to be informed of relevant health information. For individuals who choose to share their diagnosis/condition, reporting this information on the health history is most appropriate.

Many of the participants shared that their oral care experiences in dental settings were difficult. While the literature reports on behavioral challenges^{13,14,29} and multiple management strategies during oral care for children with ASD,^{13,16,17} there is no discussion regarding the effects of these experiences on young adults with ASD. Qualitative results from this study demonstrated that young adults often suffer from the time they enter the reception area until the end of their dental or dental hygiene appointment. The sounds,

sights, smells, and actual treatment can be overwhelming for an individual with ASD. Some individuals feel vulnerable based on the practitioner’s capacity to inflict pain and the their loss of control when the practitioner enters their personal space during care. Oral health care professionals may assume that as a child with ASD matures to a young adult they “get over” or that they can accommodate the treatment process. It appears that for many of the young adults with ASD, this is not the case. Their experiences are more than anxiety alone, it is sensory laden and emotionally charged. If dental professionals are to provide person-centered care, it is apparent that specific adaptations for individuals with ASD need to be learned in order to foster an environment where practitioners adapt to the patient’s needs rather than the patient adapting to the provider.

In addition, communication was a skillset that many participants expressed difficulty with. It was made clear to the researchers that some individuals with ASD do not like asking questions regarding their dental care, whereas others still had the desire to know what was going to happen throughout the visit. The literature supports socio-behavioral interventions for children using picture cards, video technology and mobile applications as a way to reduce dental anxiety and increase communication between the patient and the provider.¹⁴ However, limited literature is available to support the communication needs of the young adult. A recommendation for dental practitioners would be to provide preparation information in advance of the appointment, throughout the delivery of treatment, and after completion of procedures to anticipate and address needs, respond to questions and concerns, reduce negative emotions and feelings, and improve patient-provider relationships.

This study had limitations. The small sample of young adults with ASD precludes generalization to all adults with ASD. However, the small sample was indicative of the purpose of a qualitative study, which was to yield rich, detailed data and an understanding of a unique cohort.²⁵ Individuals who did not have oral health care treatment within the past two years were not represented. These individuals could have had profound oral health care experiences, making their stories another element to consider. Lastly, the experiences of non-verbal individuals with ASD could not be included.

Additional research related to young adults and adults with ASD is warranted. Future studies could include considerations related to those individuals who have not sought oral health care for significant periods of time and the factors that would encourage them to participate in the oral health care system. Other studies could examine oral health care professionals’

knowledge and experiences working with adults with ASD as well as skill preparation for assessing and treating patients to mitigate their oral health care sensory challenges. While the voices of verbal adult population with ASD can be readily heard, the non-verbal ASD adult population has yet to be studied. Learning their perspective about oral care experiences may be challenging, yet equally important.

Conclusion

A qualitative descriptive study was performed to investigate the oral health care experiences of young adults with an ASD diagnosis. Findings revealed that participants experienced a range of emotions related to oral health care visits. Multiple auditory, visual and tactile sensory challenges exist for the young adult ASD participants while in the reception area of the dental office as well as during treatment. Communication strategies between oral health professionals and young adults with ASD needs further development and refinement. Additional research is indicated to continue to explore the phenomenon of oral health care experiences of individuals with ASD as well as oral health care professionals' knowledge and skill preparation in delivering person-centered care to individuals with developmental disabilities.

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