

ARTICLE

Dental experiences of a group of autistic adults based in the United Kingdom

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Short informative: This is the first study in the United Kingdom to examine autistic adults' dental experiences, and it reveals that autistic adults in the United Kingdom have more negative dental experiences (linked to sensory processing, communication challenges and dental anxiety) than non-autistic adults. To improve dental care for autistic adults, we must involve patients in health care decisions, increase preparedness, and adapt the sensory environment.

[Correction added on 13 March 2021, after first online publication: Dr. Remington's surname was misspelled in the corresponding author line and has been corrected.]

1 | INTRODUCTION

Autism Spectrum Disorders (ASD) are a group of lifelong neurodevelopmental differences that manifest as social

communication difficulties (e.g., establishing and maintaining relationships) and restricted, repetitive behaviors (e.g., insistence on routines and sensory differences).¹ Autistic people comprise approximately 1.1% of the UK's

Abstract

Aims: Previous international research has shown that autistic people have difficulty accessing dental care due to sensory processing, anxiety and communication issues. However, it is not known whether autistic adults in the United Kingdom are experiencing similar dental care barriers. The current study investigated autistic adults' dental experiences in the United Kingdom.

Methods and results: A mixed methods survey was given to self-selecting autistic ($n = 37$) and non-autistic adults ($n = 43$) to compare whether autistic individuals had more negative experiences than non-autistic individuals. Closed questions asked about anxiety, patient-practitioner communication, satisfaction and the dental environment. Open questions asked about autism-specific dental challenges, what works well at the dentist, and improving autistic individuals' experiences. Responses were analyzed using thematic analysis. Overall, results demonstrated that autistic adults in the United Kingdom have more negative dental experiences than non-autistic adults. These predominantly related to interactions with dental practitioners, a challenging sensory environment, anxiety, pain, and disclosure. Participants recommended sensory environment adaptations, ways to increase preparedness, longer appointments, and individual accommodations.

Conclusion: This study offers best-practice strategies for working with autistic patients and highlights the importance of dentists working with autistic individuals to maximize the quality of care and outcomes for this underserved population.

KEYWORDS

adults, autism, dental care, dental experiences

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population,^{2,3} and many may experience lower quality of life (e.g., social isolation, co-occurring depression).^{4,5} As in current literature on the preferences of the autistic community, we have used identity first language (e.g., “autistic person”).^{6–8}

The existing data on oral health of autistic people is mixed: while an international review (India, Japan, the United States, United Arab Emirates) showed a high occurrence of dental caries and periodontal disease in autistic children,⁹ a review from the United States of autistic (average age 12) and non-autistic (average age 8) children’s records found *non-autistic* children were more likely to have dental caries, though autistic children were considered less cooperative at the dentist.¹⁰ In India, an observational study showed pediatric autistic patients had lower dental caries rates but higher periodontal disease rates than non-autistic patients.¹¹

However, while it cannot be claimed that all autistic individuals have poorer oral health than non-autistic individuals, the challenges associated with autism may impede dental care for a number of reasons. For example, differences in sensory processing can result in autistic people finding certain stimuli distressing, including loud noises, intense light, and unexpected touch-characteristic features of dental care settings.^{12,13} In the United States, parents reported that sensory stimuli including bright lights, touch near the mouth and dental products’ smell/taste were unpleasant for their autistic children and seemed linked to uncooperative behaviors.^{14–16}

Miscommunications may also limit access.¹⁷ In a recent UK semistructured interview study, the parents of autistic children emphasized the importance of communication between dentists, parents and children.¹⁸ Though no equivalent study has been conducted for autistic adults, similar issues regarding communication have been suggested about autistic adults’ interactions with health care professionals more generally. A US study¹⁹ indicated that autistic adults experienced significant general health care inequality and lower confidence interacting with health care practitioners than non-autistic adults. Follow-up interviews with autistic individuals and carers showed that successful health care interactions depended on straightforward patient-practitioner communication and allowing patients time to process information.²⁰

Another barrier may be anxiety. While not a core diagnostic feature of autism, anxiety prevalence is higher for autistic people compared to non-autistic individuals.²¹ This is particularly pertinent when considering dental care because in the general population dental anxiety is a barrier to regular attendance for 20–25% of all adults.^{22,23} For autistic people, research has indicated that sensory processing and communication difficulties increased autistic individuals’ dental anxiety.^{13,24} In a Swedish question-

naire study of 47 autistic and 69 non-autistic adults, autistic adults reported greater dental anxiety, more painful dental experiences, sensory atypicalities and lower pain tolerance than non-autistic adults.²²

There also seems to be a lack of knowledge and confidence around treating autistic patients, particularly for nonspecialist dental practitioners. A questionnaire study from the United States sought general and pediatric dentists’ views and found that while 89% of pediatric dentists treated autistic patients, only 32% of general dentists did so, indicating significant lack of support for autistic adults.²⁵ In the same study, dentists expressed feeling unprepared to treat autistic patients. A similar study reported that general dentists accepted 33% of the autistic adults and 40% of the autistic children who sought care from them.²⁶ However, if dentists felt their education prepared them well, they were more likely to accept patients with special needs.^{25,26} Other research has shown that within the United Kingdom a similar sentiment exists, with dental practitioners reporting high knowledge yet only moderate confidence when working with autistic patients.²⁷

The current study is, to our knowledge, the first to highlight the dental care experiences of UK-based autistic adults in their own words. Previous studies on the topic have focused on autistic children’s dental experiences, as reported by their caregivers,^{12,18} or examined the views of the dental professionals working with autistic individuals.²⁷ While caregivers and professionals can provide some information, incorporating autistic voices into research is crucial for ensuring quality dental care for autistic people.⁴ In addition, country-specific understanding is essential. While research has asked Swedish autistic adults about their dental experiences,²² care provision, and attitudes will differ across countries.²⁸

To address this, the current research examines the experiences of UK-based autistic adults in order to create meaningful guidance for autistic people and dental practitioners within this region. We examined whether autistic adults report more negative dental experiences (e.g., sensory discomfort, miscommunications), whether they had autism-specific challenges in accessing dental care, what worked well and what autistic adults would like to improve about their dental experiences in contrast to non-autistic individuals.

2 | MATERIALS AND METHODS

The current study used an online survey (administered via Qualtrics, Provo, UT)²⁹ which took 15–20 minutes to complete and included a total of 37 items. Total number of responses per question varied as participants completed only questions relevant to their experiences. All

procedures were approved by UCL Institute of Education Research Ethics Committee, and all participants gave written, informed consent. The final questionnaire comprised the following sections (for full details see Table 3): demographic information, dental anxiety, communication, satisfaction, details of dental experience, and qualitative questions. The dental anxiety and communication sections included components of established measures, while the other sections were bespoke for this study.

The dental anxiety section included the five-item Modified Dental Anxiety Scale,^{30,31} a dental anxiety screening tool (concerning anxiety the day before the appointment, in the waiting room, when getting a cleaning, when the dentist uses a drill and when getting an injection). Two bespoke items were added to the MDAS for the present study about anxiety one to two weeks before an appointment and when having a procedure (e.g., root canal treatment). The MDAS has an internal consistency of 0.89 and a test-retest score of 0.82, with good correspondence between raw and model data.³⁰ The MDAS has high construct validity, with associations between patients' reported dental attendance and their nervousness about treatment.³¹

The communication section included nine questions about participants' experiences with patient-practitioner communication. Six items were from the 2007 Health Information National Trends Survey (HINTS).³² The full HINTS survey (which had a total of 189 items) has good internal consistency (Cronbach's alpha = 0.90-0.92).³³ In addition to these six items, two items were added from Nicolaidis et al's (2013) study on health care access.¹⁹ These were "Dentists understand what I am trying to communicate about my dental health," and "Dentists communicate in a way that I can understand." One item on "dignity and respect" was added from the NHS Adult Dental Health Survey: Access and Barriers to Care.³⁴ No reliability or validity scores were published for the NHS survey. Items from these questionnaires were changed to specifically mention "dentists" instead of "health professionals."

Participants also reported on the frequency, dental settings and practitioners they had visited. The qualitative section differed depending on whether participants indicated they were autistic or non-autistic. The former included open-ended items about if/how participants felt autism influenced different aspects of their dental experience and requests they had made for accommodations (and their dentists' responses to these requests). Autistic participants were asked for advice for dentists who lack confidence working with autistic adults. Non-Autistic participants were asked what they would like to change (if anything) at the dentist.

TABLE 1 Participant characteristics ($n = 80$)

Characteristic	Autistic (n)	Non-Autistic (n)	N (%)
Age			
18-29	12	15	27 (33.8%)
30-39	8	9	17 (21.3%)
40-49	12	9	21 (26.3%)
50+	5	10	15 (18.8%)
Gender			
Male	9	4	13 (16.3%)
Female	27	39	66 (82.5%)
Other	1	0	1 (1.3%)
Ethnicity			
Asian or Asian British	0	3	3 (3.8%)
Black or Black British	0	3	3 (3.8%)
White or White British	35	32	67 (83.8%)
Other	2	5	7 (8.8%)
Location			
Greater London	10	23	33 (41.3%)
East Midlands	2	1	3 (3.8%)
West Midlands	1	2	3 (3.8%)
Southwest	5	1	6 (7.5%)
Southeast	4	8	12 (15.0%)
East Anglia	3	1	4 (5.0%)
Yorkshire & the Humber	3	2	4 (5.0%)
North East	2	0	2 (2.5%)
North West	0	2	2 (2.5%)
Scotland	4	1	5 (6.3%)
Wales	1	1	2 (2.5%)
Northern Ireland	2	1	3 (3.8%)

2.1 | Participant characteristics

All participants were adults over 18 who lived in the United Kingdom and who completed the survey themselves. Overall, 102 people responded to the survey, using opportunity sampling, via social media and the authors' personal networks. Participants who did not complete any questions about dentistry ($n = 18$) or reported visiting the dentist only outside the United Kingdom ($n = 4$) were excluded from further analyses. The final sample comprised 37 autistic participants (27 female; 9 male; 1 other) and 43 non-autistic participants (39 female; 4 male). Participants were from across the United Kingdom, with most from the South and Central regions of England. Significantly more autistic people lived outside of London, and significantly more non-autistic people lived in London: $\chi^2(1, n = 80) = 5.746$, $p = .017$. See Table 1 for full demographics.

TABLE 2 Additional needs reported by participants

Characteristic		Autistic	Non-Autistic
		<i>n</i> (%)	<i>n</i> (%)
Mental health need	Yes	9 (24.3%)	0 (0.0%)
	No	28 (75.7%)	43 (100.0%)
Physical health need	Yes	11 (29.7%)	3 (7.0%)
	No	26 (70.3%)	40 (93.0%)
Developmental disability	Yes	8 (21.6%)	0 (0.0%)
	No	29 (78.4%)	43 (100%)
Total	Yes	20 (54.1%)	3 (7.0%)
	No	17 (45.9%)	40 (93.0%)

Within the autistic group, 31 (83.8%) had a formal diagnosis, one (2.7%) was in the process of seeking a diagnosis and five (13.5%) answered that they were on the autistic spectrum but had no formal diagnosis. All diagnoses were self-reported by the participants. Individuals who self-diagnose were included, as self-reporting has precedents in other research, and self-report and informant measures have been shown to be highly accurate.^{35–37} Further, many people (e.g., females and adults) still struggle to receive an assessment and diagnosis of autism in the United Kingdom due to long wait times and other complicating factors.^{38,39}

Significantly more autistic participants reported an additional need than non-autistic participants; $\chi^2(1, 80) = 21.517, p < .001, d = 1.200$. Further information on additional needs is shown in Table 2.

2.2 | Data analysis

Quantitative data analyses were performed using SPSS.⁴⁰ As long as participants responded to questions about dentistry (not just demographic questions), partial responses were included, as we were reporting on individual items, rather than summing up scores for multiple items. Pearson chi-square tests (for subsections on dental visit frequency, dental experiences, anxiety, and patient-practitioner communication below) and independent *t*-tests (for satisfaction subsection below) were conducted to compare autistic and non-autistic adults' dental experiences. All statistical tests used an alpha level of $p < .05$. Effect size (Cohen's *d*) was also calculated. Similar to other studies that have examined autistic individuals' views, this study used thematic analysis and an inductive approach to analyze qualitative responses and describe themes at a semantic and informative level.^{20,41} Authors collaboratively identified potential themes, which were refined throughout analysis to ensure clear definition and coherence.

3 | RESULTS

3.1 | Quantitative analysis

3.1.1 | Dental visit frequency

Significantly more autistic than non-autistic patients only visited the dentist when in pain or emergency, rather than on a regular basis ($\chi^2(1, 11) = 6.844, p = .009$). Those who visited the dentist regularly were divided into “less than once a year group” (less than once a year, other: 15 years ago) and a “once a year or more group” (1–2 times a year, more than twice a year). There was no significant difference between the distribution of responses in the autistic and non-autistic groups; $\chi^2(1, 69) = 0.190, p = .663, d = 0.143$. Further information is provided in Table 3.

3.1.2 | Dental experiences

Autistic participants had significantly more negative overall experiences than non-autistic participants; $\chi^2(2, 78) = 7.497, p = .024, d = 0.644$. Although autistic participants showed a trend towards having more negative check-up experiences than non-autistic participants, this difference was not significant; $\chi^2(2, 75) = 5.838, p = .054, d = 0.559$. There were no differences between the treatment experience of autistic participants compared to non-autistic participants; $\chi^2(2, 75) = 3.381, p = .224, d = 0.165$. See Table 3.

3.1.3 | Satisfaction

Independent *t*-tests demonstrated that autistic participants had significantly lower satisfaction scores than non-autistic participants for dental communication ($p = .005, d = 0.722$), sensory environment ($p < .001, d = 1.21$), physical aspects of dental care ($p = .001, d = 0.797$), and knowing what was going to happen at the dentist ($p = .001, d = 0.804$). See Table 3.

3.1.4 | Anxiety

Responses were grouped into low anxiety (those who selected not anxious or slightly anxious) and high anxiety (those who selected fairly, very, or extremely anxious). Chi-squared tests indicated that significantly more autistic participants were in the high anxiety group 1–2 weeks before appointments ($p = .001, d = 0.786$), the day before appointments ($p < .001, d = 1.282$), in the waiting room

TABLE 3 Questionnaire responses regarding dental experiences, level of satisfaction, anxiety, and patient-practitioner communication. An asterisk (*) denotes significantly different responses between the autistic and non-autistic groups

Variable	Autistic	Non-autistic	p Value
Dental visits (n = 80)^a	Frequency (%)	Frequency (%)	
*Only when in pain/emergency	9 (24.3%)	2 (4.7%)	p = .09
More than twice a year	6 (16.2%)	2 (4.7%)	
1 to 2 times a year	11 (29.7%)	25 (58.1%)	
Less than once a year	10 (27.0%)	14 (32.6%)	p = .663
Never been	0 (0.0%)	0 (0.0%)	
Other	1 (2.7%)	0 (0.0%)	
*Overall dental experiences (n = 78)^a	Frequency (%)	Frequency (%)	p = .024
Positive	17 (48.6%)	33 (76.7%)	
Neutral	5 (14.3%)	6 (14.0%)	
Negative	13 (37.1%)	4 (9.3%)	
Never experienced	0 (0.0%)	0 (0.0%)	
Check-up experiences (n = 75)^a	Frequency (%)	Frequency (%)	p = .054
Positive	8 (24.0%)	19 (45.0%)	
Neutral	7 (21.0%)	12 (29.0%)	
Negative	17 (52.0%)	11 (26.0%)	
Never experienced	1 (3.0%)	0 (0.0%)	
Treatment experiences (n = 75)^a	Frequency (%)	Frequency (%)	p = .224
Positive	6 (18.2%)	7 (16.7%)	
Neutral	3 (9.1%)	10 (23.8%)	
Negative	23 (69.7%)	23 (54.8%)	
Never experienced	1 (3.0%)	2 (4.8%)	
Level of satisfaction (n = 75)^a	Mean (SD)	Mean (SD)	p Value
*Dental communication	4.6 (2.1)	5.9 (1.4)	p = .005
*Dental sensory environment	3.0 (1.8)	5.0 (1.6)	p < .001
*Physical aspects of dental care	3.3 (1.7)	4.7 (1.8)	p = .001
*Knowing what is involved at the dentist	4.4 (2.1)	5.7 (1.3)	p = .001
Anxiety (n = 75)^b	Frequency (%)	Frequency (%)	p Value
*1-2 weeks before appointment ^a			p = .001
Never experienced	0 (0.0%)	0 (0.0%)	
Low anxiety	22 (66.7%)	40 (95.2%)	
High anxiety	11 (33.3%)	2 (4.8%)	
*Day before appointment ^{t,b}			p < .001
Never experienced	0 (0.0%)	0 (0.0%)	
Low anxiety	11 (33.3%)	36 (85.7%)	
High anxiety	22 (66.7%)	6 (14.3%)	
*In the waiting room ^b			p = .028
Never experienced	0 (0.0%)	0 (0.0%)	
Low anxiety	9 (27.3%)	22 (52.4%)	
High anxiety	24 (72.7%)	20 (47.6%)	
*When getting a cleaning ^b			p = .003
Never experienced	2 (6.1%)	1 (2.4%)	
Low anxiety	9 (27.3%)	28 (66.7%)	
High anxiety	22 (68.8%)	13 (31.0%)	

(Continues)

TABLE 3 (Continued)

Variable	Autistic	Non-autistic	p Value
When the dentist uses a drill ^b			<i>p</i> = .085
Never experienced	3 (9.1%)	6 (14.3%)	
Low anxiety	4 (12.1%)	13 (30.9%)	
High anxiety	26 (78.8%)	23 (54.8%)	
When the dentist gives an injection ^b			<i>p</i> = .278
Never experienced	1 (3.1%)	4 (9.5%)	
Low anxiety	7 (21.2%)	13 (31.0%)	
High anxiety	25 (75.8%)	25 (59.5%)	
When undergoing a procedure ^a			<i>p</i> = .467
Never experienced	2 (6.1%)	6 (14.3%)	
Low anxiety	5 (15.2%)	7 (16.7%)	
High anxiety	26 (78.8%)	29 (69.0%)	
Patient-practitioner communication (n = 73)	Frequency (%)	Frequency (%)	p Value
*1. Dentists give me a chance to ask all the dental health questions I have. ^c			<i>p</i> = .045
Sometimes/never	15 (46.9%)	10 (24.4%)	
Always/usually	17 (53.1%)	31 (75.6%)	
*2. Dentists give the attention needed to my feeling and emotions. ^c			<i>p</i> = .040
Sometimes/never	21 (65.6%)	13 (31.7%)	
Always/usually	11 (34.4%)	28 (68.3%)	
*3. Dentists involve me in decisions about my dental health as much as I want. ^c			<i>p</i> = .047
Sometimes/never	14 (43.8%)	9 (22.0%)	
Always/usually	18 (56.3%)	32 (78.0%)	
4. Dentists make sure I understand the things I need to do to take care of my dental health. ^c			<i>p</i> = .089
Sometimes/never	10 (31.3%)	6 (14.6%)	
Always/usually	22 (68.8%)	35 (85.4%)	
*5. Dentists help me deal with feelings of uncertainty about my dental health and care. ^c			<i>p</i> = .024
Sometimes/never	21 (65.6%)	16 (39.0%)	
Always/usually	11 (34.4%)	25 (61.0%)	
*6. Dentists understand what I am trying to communicate about my dental health. ^d			<i>p</i> = .024
Sometimes/never	15 (46.9%)	9 (22.0%)	
Always/usually	17 (53.1%)	32 (82.9%)	
*7. Dentists communicate in a way that I can understand. ^d			<i>p</i> = .025
Sometimes/never	13 (40.6%)	7 (17.1%)	
Always/usually	19 (59.4%)	34 (82.9%)	
*8. I feel that I can trust dentists to take care of my dental health care needs. ^c			<i>p</i> = .012
Sometimes/never	16 (50.0%)	9 (22.0%)	
Always/usually	16 (50.0%)	32 (78.0%)	
*9. I feel that my dentists treat me with dignity and respect. ^e			<i>p</i> = .001
Sometimes/never	15 (46.9%)	4 (9.8%)	
Always/usually	17 (53.1%)	37 (90.2%)	

^aBespoke measures for the current study.^bModified Dental Anxiety Scale (MDAS).^{30, 31}^cHealth Information National Trends Survey (HINTS).^{32, 33}^dNicolaidis et al (2013).¹⁹^eNHS Adult Dental Health Survey: Access and Barriers to Care.³⁴



FIGURE 1 (A) Diagram of themes and subthemes relating to dental experiences. Solid lines indicate themes shared by autistic and non-autistic participants. Dashed lines indicate themes raised only by autistic participants. (B) Diagram of themes and subthemes relating to recommendations. Solid lines indicate themes shared by autistic and non-autistic participants. Dashed lines indicate themes raised only by autistic participants

($p = .028$, $d = 0.518$), and when having a cleaning ($p = .003$, $d = 0.577$). Both autistic participants and non-autistic participants experienced high anxiety when the dentist uses a drill ($p = .085$, $d = 0.433$), when the dentist gives an injection ($p = .278$, $d = 0.378$) and when undergoing a procedure ($p = .467$, $d = 0.268$). See Table 3.

3.1.5 | Patient-practitioner communication

Almost all items in this section were rated differently by the two groups. Chi-squared tests indicated that autistic participants more often felt that dentists did not give necessary attention to their emotions ($p = .040$, $d = 0.712$), did not help them with feelings of uncertainty around their dental care ($p = .024$, $d = 0.544$), and did not give them opportunity to ask all the questions they had ($p = .045$, $d = 0.492$). Autistic participants were less likely to feel included in decisions about their dental care ($p = .047$, $d = 0.476$) and less frequently felt that their dentist understood what they were communicating ($p = .024$, $d = 0.543$). Similarly, they were less likely to feel they understood dentists ($p = .025$, $d = 0.540$) or could trust the dentist ($p = .012$, $d = 0.610$), and less often felt that they were treated with dignity and respect ($p = .001$, $d = 0.919$).

Only item 4, “Dentists make sure I understand what I need to do to take care of my dental health,” showed similar responses for autistic and non-autistic participants ($p = .089$, $d = 0.404$). See Table 3.

3.1.6 | Qualitative analysis

Regarding participants’ experiences accessing dental care, five themes emerged: interactions with dental practitioners, a challenging sensory environment, anxiety, pain and disclosure. Autistic ($n = 29$) and non-autistic ($n = 28$) participants also shared recommendations for improving dentists’ practices. Because qualitative questions were optional, overall response totals across the two groups varied by question (from $n = 72$ to $n = 80$). (See Figure 1 for all themes, and Table A1 in Appendix A for example quotes for each theme.)

Theme 1: Interaction with dental practitioners. Many autistic ($n = 35$) and non-autistic ($n = 32$) participants shared at least one negative dental experience, often linked to communication with dentists. Five autistic participants reported *feeling misunderstood*, “even when I think I’m being clear” (A007). Another issue, mainly for autistic people ($n = 6$, one non-autistic participant) was a *lack of voice*. Further, some autistic ($n = 17$) participants and one non-autistic participant felt that “dentists act like I’m making excuses” (A013).

Several participants spoke about *consistency*, though views were mixed. Some (four autistic, one non-autistic), felt that dentists were inconsistent: “they can never say who is going to see me” (A036). Others (four autistic, one non-autistic) reported good consistency: “I’ve been seeing the same dentist since I was five which helps. . . I know him and what to expect” (A029). Indeed, two autistic participants travelled to their dentist because they were familiar.

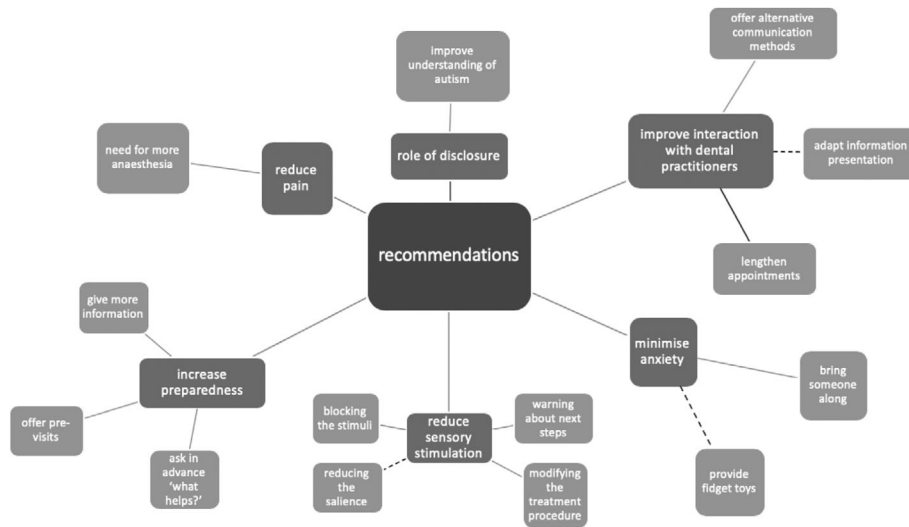


FIGURE 1 Continued

Two autistic participants indicated that they stopped going to the dentist entirely when their dentist moved.

Overall, 7 autistic and 10 non-autistic participants had positive communication experiences. It was appreciated when dentists “provided opportunities to ask questions” (NA040). Likewise, three autistic and two non-autistic participants elaborated on the *benefit of accommodations*. For instance, one participant’s dentist “didn’t make me wait; took me straight in and let me feel comfortable” (A037). Two autistic and four non-autistic participants shared that their experience *improved in adulthood*: “as an adult, I have more respect and more control” (A017).

Where experiences were less positive, autistic ($n = 24$), and non-autistic ($n = 9$) participants suggested improvements. Most improvements centered on ways that communication could be modified, for example by *adapting information presentation*. Six autistic participants recommended that dentists should ensure “everything is in writing” for reading about procedures beforehand (A034). Other participants recommended “more visual information” (A039) and Social Stories™. One participant advised, “don’t ask rapid fire questions” (A016). Three autistic and one non-autistic participants requested dentists *offer alternative communication methods*: an “action I can do to let [dentists] know I’m not coping” (NA026) and “other ways to make appointments than phoning” (A012). Autistic ($n = 9$) and non-autistic ($n = 8$) participants recommended *lengthening appointments*.

Theme 2: Preparedness. A separate, but associated set of experiences and recommendations were related to *preparedness*, with both autistic ($n = 6$) and non-autistic ($n = 4$) participants commenting: “I dislike not being told I’m going to be touched” (A015). Four autistic participants felt “if *unexpected questions* arise, it throws my head in a

tailspin” (A004). However, some participants (five autistic and six non-autistic participants) reported positive experiences of their *dentists previewing procedures*: “they tell me what they’ll be doing, even if it’s a routine I’ve been through” (A037). Recommendations were also made around *increasing preparedness*, including a request from 14 autistic and 9 non-autistic participants for dentists to *provide more information*. Additionally, 14 autistic and 1 non-autistic participants recommended dentists “ask in advance what would (and wouldn’t) help” (A013). Five participants emphasized “listen[ing] to the patient” (A016) and “do[ing] whatever possible in response” (A004). Two other recommendations, tied to anxiety and disclosure, respectively, were related to a sense of preparedness: “offer pre-visits” (1 autistic and 1 non-autistic participant) and “improve understanding of autism” (15 autistic and 3 non-autistic participants).

Theme 3: Challenging sensory environment. Both autistic ($n = 27$) and non-autistic ($n = 3$) participants had sensory concerns. Some (15 autistic and 3 non-autistic participants) experienced *unpleasant touch*: “unpleasant being touched by a stranger” (A027) and some autistic participants ($n = 3$) experienced *vestibular/balance* issues: “lying on my back... makes me feel vulnerable” (A004). Many autistic participants found the entire dental environment *overstimulating* ($n = 27$): “[dental surgeries] smell. They are bright. They are loud. I hate it.” (A034). Three autistic participants mentioned smells and lights were overwhelming: “Bright lights cause migraines” (A031). Sounds were also problematic: “hard to block them out even with headphones or ear plugs” (A021).

Many autistic participants ($n = 15$), and three non-autistic participants, made recommendations for reducing the sensory impact of the environment. These included

blocking the stimuli (“as long as I wear sunglasses, it’s not too bad” (A027) or *reducing the salience* of the sensory concern (e.g., turning the lights down). Other participants recommended *modifying the treatment procedure*. For instance, two autistic participants recommended they “be allowed to sit up more” (A020) to alleviate vestibular issues. Another participant preferred certain instruments be avoided, while two autistic and one non-autistic participant preferred specific instruments to be used. Two autistic and one non-autistic participant felt there should be a *warning about sensory input*. For instance, one participant recommended, “tell me before you touch me” (A013).

Theme 4: Anxiety. Many participants (23 autistic, 15 non-autistic) experienced dental anxiety. For some (2 autistic, 9 non-autistic), this was due to the *impact of past experiences*: “traumatic ortho[dontics]... put me off all dentistry” (A018). This was echoed by six non-autistic and two autistic participants who shared that, “positive childhood experiences kept anxiety low in adulthood” (NA023). Other than the impact of past experiences, three autistic participants’ anxiety was *caused by the sensory environment*.

When considering the outcomes of their anxiety, 15 autistic participants felt anxiety *affects communication*. One participant explained, “I am less likely to complain...as I am too anxious to say” (A010). For six autistic and five non-autistic participants, anxiety *reduces attendance*: “I feel very anxious about going... I often cancel appointments or put off going for as long as possible” (A021). Two autistic and one non-autistic participants felt their anxiety was *dismissed by dentists*.

To lessen anxiety, participants recommended *bringing someone along* to support them during the visit (five autistic and two non-autistic participants) and using *fidget toys* (one autistic participant). Both autistic and non-autistic participants mentioned that increasing preparedness (see above) may also help alleviate anxiety.

Theme 5: Pain. Autistic ($n = 15$) and non-autistic ($n = 11$) participants mentioned experiencing pain while at the dentist. In many cases (2 autistic, 6 non-autistic) the pain *varies by procedure*. For some ($n = 6$), mostly autistic ($n = 5$) participants, pain was associated with a *need for more anesthesia*. One non-autistic participant (NA026) shared, “I told the dentist my body resists anaesthetic. I was told...go on with the procedure. I...was in terrible pain.” Three autistic participants and one non-autistic participant shared information about their pain thresholds, “I experience pain very intensely in my mouth” (A008).

Some participants expressed *appreciation of sensitive dentists* (autistic $n = 3$, non-autistic $n = 2$): “they check in with me and can tell if I’m in pain” (A007). Two autistic and one non-autistic participants’ experiences were *helped by medication* (e.g., diazepam) and seven autistic and one

non-autistic participants felt *more anesthesia* would help: “so I am unaware of the procedure” (A028).

Theme 6: Disclosure. Eleven autistic participants spoke about disclosure of their autism diagnosis. Four participants felt *disclosure does not help*: “when I’ve previously told dentists I’m autistic, it appears to have largely been ignored” (A012). Four other participants felt that their dentists *lacked autism understanding* and even exhibited “arrogance, not understanding” with respect to autism (A009). Another autistic participant advised, “don’t assume you know anything about autism” (A024).

Views on the importance of disclosure were mixed. While three autistic participants felt there was *no need to disclose*: “I haven’t disclosed my autism but care is good anyway” (A007), others (15 autistic and three non-autistic participants) felt it was important that dentists *improve their understanding of autism*. Ten autistic participants gave insights about how understanding autism can help dentists modify their practices accordingly: “ASD is different for everyone...it’s important to know each person to understand what helps them through the process” (A003). Five autistic and three non-autistic participants recommended dentists get to know their patients: “The only way to get familiar with autistic people is by interacting with autistic people” (A039).

4 | DISCUSSION

While a number of participants shared positive practices, and appreciated the time that dentists spent with them, this study demonstrated that autistic adults have more negative overall dental experiences than non-autistic adults. Those on the autistic spectrum are also more likely to visit the dentist only when in pain, rather than for regular check-ups.

Many of the negative experiences were related to core features of autism, such as communication and sensory processing challenges. Significantly fewer autistic participants felt understood by dentists or understood what dentists communicated. Many autistic participants felt anxious or inhibited when confronted with unexpected questions or needed time to process information about procedures. Similar to the results of previous studies^{18,27} with parents of autistic children, our participants’ interactions with the dentist were negatively impacted by short appointments. Autistic participants reported feeling rushed and uninvolved in their dental health, and significantly fewer autistic participants felt their questions were answered. Thus, feeling rushed added to already existing communication barriers. Accordingly, time to ask questions and interact with the dentist were found to be intrinsic to improving the experience.

Worryingly, more autistic individuals (compared to non-autistic individuals) felt that their concerns were not acknowledged and that they were not treated with dignity and respect. This was not a finding in previous dental studies, perhaps because they did not directly ask autistic people about their experiences. Our findings map onto those of a previous study which found autistic people felt dismissed by general medical professionals.¹⁹ However, unlike that study,¹⁹ our study looked specifically at experiences with dentists instead of general health care professionals and provided qualitative insights as to why, or how, people felt they were being dismissed (e.g., dentists ignored their requests for accommodations). The feeling of not being treated with dignity and respect was linked to a need for increased communication and getting to know patients as individuals.

To address these concerns, participants suggested frequently checking in to minimize miscommunications as well as listening and responding to the patient. While not all dentists can accommodate an increased appointment length (e.g., NHS practices), participants indicated that even five additional minutes would help.

Sensory aspects of the dental environment were also a key concern for autistic participants, echoing previous research.^{16,18} Our study revealed specific reasons behind such concerns, building on previous studies which reported accounts from caregivers' about their child's experiences. For instance, in these previous studies, a parent stated "all the sensory devices just make him so uncomfortable"¹⁶ without sharing why they made him uncomfortable. In the current study, participants expressed the reasons behind their discomfort with the sensory environment, which enable best-practice recommendations to be made regarding adjustments that can ameliorate such distress. Qualitative responses about "blinding lights" and "intense" and "upsetting" noises indicate clearly why satisfaction with the sensory environment is low. Previous dental studies have suggested implementing broad changes to the dental environment including calming music and weighted blankets,⁴² yet recommendations varied widely in the current study, including suggestions about wearing sunglasses, turning off the radio, and lowering the dental chair before the individual sits down.

In line with previous literature, both autistic and non-autistic participants commonly remarked on dental anxiety.^{22,43} However, while the previous study¹⁹ focused mainly on the connections between anxiety and pain, our study's participants emphasized how interactions with the dentist can either increase or decrease anxiety, depending on the nature of the interaction. Autistic participants, however, experienced significantly more anxiety before appointments and during dental check-ups, whereas non-

autistic participants' anxiety increased only for injections and procedures. Participants recommended that exploring ways to reduce anxiety for all patients should be considered a priority. They also acknowledged that autistic patients' anxiety may begin before appointments and inhibit communication, highlighting the need for accommodations to be implemented from appointment scheduling onwards to ensure that participants are able to fully communicate their experiences and dentists can understand how they feel. In keeping with a review that showed dental patients felt less anxious when they understood their treatment,⁴⁴ participants suggested that better explanations of procedures may prevent some anxiety.

Though we have made a number of recommendations above, the importance of an individualized approach must be emphasized. The findings of the current study indicate that dentists should involve patients in making decisions about their individual, preferred accommodations. This will improve their dental health visits and increase autonomy.

4.1 | Limitations

Though this study provides a foundation for understanding autistic adults' dental experiences in the United Kingdom, a number of questions remain. UK dental training includes special care and autism awareness lectures, yet pediatric and special care dentists are more likely to receive autism training and accept autistic patients.^{25,27,28} Future research should examine if autistic people's experiences differ depending on which dentist they attend.

The nature of our sample also presents a variety of limitations. First, participants were not required to have a formal diagnosis of autism to contribute to the autistic group. Although it has been noted that including self-diagnosed autistic adults adds knowledge about autistic individuals who may struggle to receive a formal diagnosis for various reasons, further research should compare the experiences of autistic adults with and without formal autism diagnoses.

While the survey was distributed throughout the United Kingdom, most of our participants were from the South and Central (and potentially urban) areas of England. Thus, we recognize that individuals in other regions of England, as well as Scotland, Wales, and Northern Ireland were not adequately represented. Given the country-specific milieu that may impact on dental provision, this may undermine the generalizability of our findings. Additionally, the sample size was fairly small, particularly with respect to the quantitative statistics. However, large effect sizes provide reassurance regarding the conclusions drawn, and saturation was reached with the qualitative responses, thus suggesting an appropriate sample size.⁴⁵

Additionally, though efforts were made to reach a broad audience, only participants with access to technology were able to participate in this survey, limiting the representativeness of the sample. It is likely that this excludes the estimated 30% of autistic people who are minimally verbal, and many of those with co-occurring intellectual impairment. While such people would likely not have been able to share their dental experiences in the present study, they may experience even greater barriers to dental care than our current participants. Future research should seek to include a wider range of voices.^{46,47}

5 | CONCLUSIONS

In conclusion, the current study extends previous work to consider autistic adults' dental experiences in the United Kingdom. Results showed that, similar to previous studies on autistic children's experiences, autistic adults in the United Kingdom have more negative overall dental experiences than non-autistic adults, generally due to sensory processing, communication challenges and dental anxiety. These negative experiences were also linked to specific issues such as short appointments and a perceived lack of dignity and respect. In some instances, autistic participants felt that dentists did not believe their concerns or discomfort. The latter was an issue that had not arisen in previous research, highlighting the importance of including first-hand reports and not relying solely on caregiver reports.

Participants also reported examples of good practice when their dentists allowed time to ask questions before a procedure began. Further, participants recommended accommodating individual needs, and involving the patient in those decisions. Our results indicate that dentists can improve their practice by working directly with autistic people within their training programmes and practice to adapt information presentation and other aspects of communication, increase preparedness, provide options to block or reduce sensory stimuli, and learn more about their patients as individuals. The current study therefore lays the foundation for further collaborative research about autistic adults' dental experiences in the United Kingdom.

DATA AVAILABILITY STATEMENT

Explicit permission was not given by participants for public archiving of the data; however an anonymized dataset is available from the authors on request.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

ETHICS STATEMENT

All procedures were approved by UCL Institute of Education Research Ethics Committee, and all participants gave written, informed consent.

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APPENDIX A: ILLUSTRATIVE QUOTES

TABLE A1 Example quotes for each theme regarding experiences and recommendations. Experience themes are emboldened, while recommendation themes are not. An asterisk indicates which themes and subthemes were found only in the responses of autistic participants

Theme	Subtheme	Illustrative quotes
Interactions with dental practitioners	*Feeling misunderstood	"I'm not sure what the right thing to say is, how to describe things, what is too much information." (A026)
Improve interaction with dental practitioners	Lack of voice	"I might not say what I want to or express my worries." (A001)
	Consistency	"Have been... phobic of dentists my whole life because it was assumed I was lying or being overdramatic." (A017)
	Benefit of accommodations	"I requested the light be turned down slightly and the music turned off... requests refused." (A016).
	Improvements in adulthood	"Dentist has gone against my wishes..." (A029)
	*Adapt information presentation	"I moved dentists a lot during my childhood so no consistency of care." (NA034)
	Offer alternative communication methods	"I had a fantastic dentist... he retired and new dentist was clinical and fast-paced." (A010)
	Lengthening appointments	"I have been with the same dentist for nearly 30 years... they provide a good service" (NA034).
		"Emailed surgery and asked to book quieter times; given suggested times to visit." (A012)
		"I don't like it, but my current dentist is very careful and gentle." (A030)
		Same level of nervousness but easier to communicate as an adult." (NA030)
		"Increased availability of visual information." (A037)
		"have alternative ways of communicating to make sure everything is understood." (A014)
		"slightly more time to chat before a procedure to alleviate any concerns." (NA014)
Preparedness	Dislike not being told	"It is extremely uncomfortable to be touched and there is never any warning." (A014)
Increase preparedness	*Unexpected questions	"I struggle to process the information because even when they explain it it sometimes takes a few minutes before I've understood what they have said but by then they have already started." (A038)
	Dentists preview procedures	"What made this positive was having information about what was going to happen and why at each stage." (NA003)
	Give more information	"Information... helps get rid of anxiety and makes sure everyone is on the same page." (A012)
	Ask in advance "what helps?"	"To ask their patients what they need on an individual basis... understanding the individual is key to... reduce their [dentist's] lack of confidence." (A001)
	Offer pre-visits	"Ask the individual... to explain anything that will make treatment easier." (A022)
		"Remember autistic people are all different so what works for one might be horrific for another." (A013)
		"Allowing for a pre-visit to familiarise myself with the dentist and the facilities would help." (A039)

(Continues)

TABLE A1 (Continued)

Theme	Subtheme	Illustrative quotes
Challenging sensory environment Reduce sensory stimulation	Unpleasant touch *Vestibular issues *Overstimulating Blocking the stimuli *Reducing the salience Modifying the treatment procedure Warning about next steps	“Person doing suction always presses too hard.” (A002) “It’s not so much the pain as the weird vibration when they drill or clean.” (A027) “I hate lying down... I can’t see what’s going on behind me. Hate it.” (A009) “the smells... increase my tension” (A017) “Sounds of equipment can seem very intense and upsetting even if I am not in pain.” (A022) “I really really struggle with this... bright artificial light... which is quite blinding.” (A012) “Everything is too bright and too echoey. This makes it more difficult to concentrate and means I’m more likely to just dissociate.” (A004) “when I was younger, I used to get sunglasses to help.” (A038) “I can listen to my own music.” (A037) “removing background aromas.” (A037) “They avoid strong smells where possible.” (A037) “music turned off.” (A016) “Dimmer lights.” (A008) “Lights turned off.” (A012) “I just need a friendly, nonrushed environment.” (A010) “having the chair lowered before I lie down.” (A024) “knowing what will happen, especially if there will be physical contact... can help put us at ease.” (A026)
Anxiety Minimize anxiety	Impact of past experiences *Caused by sensory environment *Affects communication Reduces attendance Bringing someone along *Provide fidget toys	“In childhood, [my dental experiences] were very poor and I was quite traumatised by them.” (A022). “never had an issue with the dentist and that’s not changed as I’ve grown up.” (NA037) “I have never had a bad experience... however it is always neryv having to go.” (NA027) “Sensory... needs were not known when I was a child so therefore were not met, leading to enormous anxiety.” (A037) “I am so anxious about visiting the dentist that I often don’t feel able to speak and also can’t process what the dentist is saying to me.” (A014) “I can get too anxious to speak or ask certain questions.” (A030) “As a child, going to the dentist was a routine. Now I go less as an adult as it’s more anxiety provoking.” (NA013) “I have dissociated or left by this point.” (A009) “Having someone with me.” (A020) “Having fiddle/stimming toys available.” (A038)

(Continues)

TABLE A1 (Continued)

Theme	Subtheme	Illustrative quotes
Pain Reduce pain	Need for more anesthesia	"I have to be sedated for anything more than a cleaning." (A030)
	Varies by procedure	"I am rather under sensitive to pain when it comes to the mouth. This means I am more likely to neglect dental decay because I can hold on for longer." (A039)
	Appreciation of sensitive dentists	"I experience pain very intensely in my mouth." (A008)
	Helped by medication	"had frequent trips to the orthodontist which always made me feel very anxious." (NA016)
	Need for more anesthesia	"My dentist was sympathetic and suggested I don't experienced pain as expected, and perhaps as a result have poorer teeth." (A015) "well anaesthetised so less pain than I can tolerate." (A019) "Make me unconscious on arrival." (A028)
Role of disclosure Role of disclosure	*Disclosure does not help	"When I've previously told dentists I'm autistic, it appears to have been largely ignored." (A028).
	*Lack of autism understanding	"The staff are clueless about autism and how best to manage me." (A038).
	*No need to disclose	"I haven't disclosed my autism but her care is good anyway." (A007)
	Improve understanding of autism	"We are still just people. Autism is simply a different neurological set-up, so autistics just perceive the world a little differently." (A026)
		"ASD is an information and sensory processing condition which is different for everyone, so it is important to get to know each patient to understand what helps them process information and what may overwhelm them." (A008)