Running head: Dental professionals' confidence in treating autistic patients
UK dental professionals' knowledge, experience and confidence when treating patients on the
autism spectrum
Demi Eades ¹ , Patricia Leung ¹ , Aaron Cronin ² , Joana Monteiro ³ , Adele Johnson ³ , & Anna
Remington ¹
¹ Centre for Research in Autism and Education, Department of Psychology and Human Development, UCL Institute of Education, University College London, UK
² King's College Hospital, London, UK
³ Eastman Dental Hospital, London, UK

Dental professionals' confidence in treating autistic patients

Abstract

Background: Over 1% of the UK population have a diagnosis of autism, and yet there is minimal information regarding the experiences of dental professionals working with people on the autistic spectrum. The current study is the first to investigate UK dental professionals' knowledge of autism, their perceived confidence when treating autistic patients, and the factors that affect this.

Methods: An online, self-report survey was completed by 482 UK dental professionals and included questions on participants' training, prior experiences and knowledge of autism, and confidence when treating autistic patients.

Results: Over half the respondents reported having no formal autism training however average knowledge levels across the whole sample were good. Conversely, levels of confidence were only moderate. Respondents often cited conflict between understanding the additional needs for successful treatment of autistic patients and a lack of resources to implement support strategies. Despite this, the vast majority were positive about making the necessary modifications to support autistic patients.

Conclusion: This study highlights ways in which UK dental professionals adapt their practices to meet the needs of their autistic patients, yet report only moderate confidence levels when doing so. Implications for future training initiatives are discussed.

Dental professionals' confidence in treating autistic patients

In brief:

- First study in the UK to investigate the knowledge level and confidence of dental practitioners when treating autistic patients
- Results reveal techniques UK dental practitioners are currently using to treat their autistic patients and identify what challenges they are facing
- Findings inform recommendations regarding best practice in dental care for autistic people.

Autism is a developmental condition associated with social communication difficulties, and the presence of rigid, repetitive behaviours and atypical sensory sensitivities. As such, the nature of dental procedures and the treatment environment may prove a particularly challenging area for individuals on the autistic spectrum. In particular, sensory atypicalities may pose a barrier to treatment. Many autistic individuals are hypersensitive to a multitude of stimuli such as bright lights, noise and touch. Accordingly, parents of autistic children reported more difficulty in having a dentist or hygienist clean their child's teeth (63%), compared with only 13% of parents with typically developing children.² Further autism-specific challenges include communication difficulties between dental practitioner and patient, which has been reported to be a key element in failed or unpleasant dentist visits for autistic adults in both the US and UK³⁻⁵. Given the bi-directional nature of communication, the dental practitioner clearly plays a crucial role in overcoming this area of challenge. Repetitive, rigid behaviours, such as flapping, rocking, making certain sounds or more serious self-harm behaviours such as head banging, can also make dental treatments difficult, due to an inability to safely access the patient's mouth, or safety concerns regarding the patient not being able to remain still enough for treatment. 6-7

Though not part of the core diagnostic criteria, autistic people also have higher levels of co-occurring mental health conditions such as anxiety. While visits to the dentist can provoke anxiety in many (with around 36% of adults having some form of dental anxiety),⁸ the increased susceptibility to clinical levels of anxiety can make dental visits particularly distressing for autistic individuals.⁹⁻¹²

In line with all these challenges discussed above, several studies (conducted in the US and Saudi Arabia) regarding the dental experiences of autistic people have reported

significant difficulties in accessing adequate dental care.^{2, 13-15}. This has wide-ranging consequences: poor oral health care can lead to pain, eating difficulties and speech impairments amongst other ailments. That these are more common in autistic patients, suggests a need to examine oral healthcare policies for this population.¹⁶

Worryingly, it has been suggested that dental professionals' attitudes may be part this problem. Parents of autistic children in both the US and the Netherlands have often reported struggling to find a dental practitioner willing to treat their child, with up to 25% of children being turned away from dental clinics.^{6,17} Indeed, when asking dentists in the United States whether they would treat patients with a range of special healthcare needs, autistic adults were the least accepted group, with only 33% of practitioners being willing to treat them, and only 40.1% willing to care for autistic children.¹⁸

This unwillingness may in part be due to a lack of training received, with the quality and type of dental education said to be a predictor of dental practitioners' self-competence and willingness to provide care for patients with special care needs. In US studies General Dental Practitioners (GDPs) have reported that their training did not adequately equip them with the skills necessary to treat their special needs patients, and as such, they do not feel confident in doing so.^{6,18} Conversely, pre-doctoral autism training undertaken whilst at university is associated with positive attitudes, a willingness to treat autistic patients and an interest in undertaking further training.¹⁹⁻²⁰ Consequently, autistic people in the US have called for increased training to be given to GDPs.^{3,21} To date, the effect of dental training on the confidence of UK dental professionals remains unresearched.

The few studies conducted in the UK have focused on the experiences of autistic individuals and their families. No UK-based research has examined the experiences of dental

professionals, who play an integral role in ensuring adequate treatment. Thus, gaining an understanding of UK dental professionals' current level of knowledge and confidence is vital in aiding the transformation of dentistry services and addressing inequalities in oral health care that currently exist.²²

The current study investigated UK dental practitioners' (a) experience treating autistic patients; (b) knowledge of autism (c) perceived self-efficacy when treating autistic patients, and the factors that affect this.

Materials and Methods

Dental professionals from across the UK were invited to take part in an online questionnaire (powered by Qualtrics). All responses were collected anonymously, and all participants gave informed consent before completing the survey. Ethical approval for this study was attained via the Research Ethics Committee at UCL Institute of Education, University College London. The survey contained three parts and took approximately 10 minutes to complete. Part 1 consisted of 14 questions about participants' background information, including demographics (age, gender, ethnicity, location), years in practice, their specific dental profession and practice setting, contact with autistic patients and prior autism training. Part 2 included a *Knowledge of Autism Scale*, comprised of 15 statements which assessed participants' knowledge of the core features of autism, including early signs of autism, characteristics and common co-morbidities. The scale was modified from a previous study looking at GP's knowledge of autism²³ to include questions relevant to a dental professional, e.g. "people with autism can show unusual reactions to sensory experiences (e.g. lights, touch, sounds etc.). Participants were required to score items as 'true' or 'false,'

with one point given for each correct answer. Item scores were then summed to produce a total score (higher scores indicate a greater knowledge about autism).

Part 3 consisted of a *Self-Efficacy Scale*. Perceived self-efficacy, is the belief in one's ability to execute behaviours necessary to achieve goals, which can change between situations.²⁴ The scale used in this study was adapted from that used by Unigwe et al²³ and was modified to effectively assess dental professionals' perceived self-efficacy when working with patients on the autism spectrum. Participants were asked to rate 8 items (e.g. how confident do you feel in knowing what adjustments could be made to facilitate treatment for autistic people) on a 7-point Likert based confidence scale (from 1 = not at all confident; through 4 = somewhat confident, to 7 = extremely confident). Individual item scores were averaged to produce a mean self-efficacy score; a higher score reflected greater self-efficacy. The scale showed excellent internal consistency (Cronbach's $\alpha = .907$).

Two open-ended questions were included in the survey. Participants were asked to list any techniques they use to treat autistic patients and were given the opportunity to outline successes, challenges and overall experiences of working with autistic patients.

Data analysis

Data analysis was undertaken using IBM SPSS Statistics version 25.²⁵ Correlational analyses were conducted to assess relationships between knowledge of autism, self-efficacy and other key variables. T-tests (or Mann-Whitney U where data did not meet the assumptions for parametric testing) were used to compare the knowledge and self-efficacy levels between those with and without personal experience of autism, and those who had

received autism training versus those who had not. Due to the large number of comparisons, Bonferroni adjusted alpha levels of .0125 were used for all four comparisons.

Responses to open-ended questions were considered qualitative data. While there is a diversity of opinion regarding the validity of this approach, ^{26,27,28} we have followed the precedent set in similar research on experience of other professional groups working with autistic individuals. ^{23,29} All qualitative responses were analysed using thematic analysis. ³⁰ An inductive approach was employed, allowing authors to identify and describe clear themes at semantic level in response to the data set, rather than placing responses into pre-defined themes. Authors independently familiarised themselves with the data, through reading and rereading, then worked together to produce a list of preliminary themes and subsequently assign codes to each response independently. Potential themes were reviewed and refined frequently during analysis using Patton's dual-criteria, ³¹ to ensure internal coherence within themes and distinctions between themes. ³¹

Results

A total of 482 dental professionals were recruited via the NHS dentist directory, distribution lists of professional bodies such as the British Orthodontic Society and British Society for Paediatric Dentistry, and snowballing methods through dentists' referrals and on social media thereafter. Participants were excluded if they did not progress past part 1 of the survey (n=125), leaving a final sample of 357. The majority of the sample was female and White British, but with varying age and years in practice (see Table 1 for full demographics). Overall, 38.7% (n=138) of respondents reported having some personal experience of autism, through being autistic themselves (n=1; 0.3%); having an autistic child (n=28; 7.8%); relative

(n=48; 13.4%) or colleague/friend (n=55; 15.4%). Six respondents did not answer this question.

Table 1. Participant characteristics, n=357

	Characteristic	<i>n</i> (%) ^a
Age		
	Mean: years (SD)	44.60 (10.74)
	Range: years	22- 70
Gender		
	Male	94 (26.3)
	Female	259 (72.5)
	Prefer not to say	5 (1.2)
Ethnicity		
	White background	300 (84.0)
	Black background	1 (0.3)
	Asian background	43 (12.1)
	Mixed background	4 (1.1)
	Any other ethnic group	6 (1.7)
	Prefer not to say	3 (0.8)
Country of primary qualification	n	
	England	243(68.1)
	Northern Ireland	11(3.1)
	Scotland	51(14.3)
	Wales	13(3.6)
	Other	39(10.9)
Years in practice as a dentist		, ,
-	Mean: years (SD)	20.80 (11.20)
	Range: years	<1 – 45
Location of dental practice		
-	North East	21 (5.9)
	North West	45 (12.6)
	Yorkshire and The Humber	34 (9.5)
	East Midlands	17 (4.8)
	West Midlands	25 (7.0)
	East of England	15 (4.2)
	London	40 (11.2)
	South East	51 (14.3)
	South West	36 (10.1)
	Wales	14 (3.9)
	Scotland	40 (11.2)

NHS provision 179 (50.0) Private practice 43 (12.2) Mixed 135 (37.8)		Northern Ireland Did not answer	16 (4.5) 3 (0.8)
NHS provision 179 (50.0) Private practice 43 (12.2) Mixed 135 (37.8)	Sector of work		
Private practice A3 (12.2) Mixed Mixed 135 (37.8) Role (all that apply) General Dental Practitioner For (18.8) Paediatric Dentist For (18.8) Paediatric Dentists For (18.4) Paediatric Dentist For (18.4) Paediatric Dentist For (18.4) Paedi	Sector of work	NHS provision	179 (50.0)
Role (all that apply) General Dental Practitioner For (18.8) Paediatric Dentist For (18.8)		-	, ,
Role (all that apply) General Dental Practitioner 67 (18.8) Paediatric Dentist 58 (16.2) Special Care Dentist 30 (8.4) Dental Nurse 37 (10.4) Hygienist 16 (4.5) Orthodontist 131 (36.7) Therapist 14 (3.9) Community Dentist 8 (2) Other 42 (11.8) Practice General Practice 129 (36.1) Community Practice 68 (19.0) Hospital 105 (29.4) Other 54 (15.5) Hours/week patient contact Mean: hours (SD) 19.23 (8.60) Range: hours 2 - 41 Knowingly treated autistic patients Autistic children 123(34.5) Autistic adults 7(2.0) Rot sure 49 (15.2) No 7(2.0) Not sure 49 (15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		-	
General Dental Practitioner 67 (18.8) Paediatric Dentist 58 (16.2) Special Care Dentist 30 (8.4) Dental Nurse 37 (10.4) Hygienist 16 (4.5) Orthodontist 131 (36.7) Therapist 14 (3.9) Community Dentist 8 (2) Other 42 (11.8) Practice	Role (all that apply)		,
Special Care Dentist b 30 (8.4)		General Dental Practitioner	67 (18.8)
Dental Nurse		Paediatric Dentist ^b	58 (16.2)
Hygienist 16 (4.5) Orthodontist 131 (36.7) Therapist 14 (3.9) Community Dentist 8 (2) Other 42 (11.8) Practice General Practice 129 (36.1) Community Practice 68 (19.0) Hospital 105 (29.4) Other 54 (15.5) Hours/week patient contact Mean: hours (SD) 19.23 (8.60) Range: hours 2 - 41 Knowingly treated autistic patients Autistic children 123(34.5) Autistic adults 7(2.0) Both children and adults 216(60.5) No 7(2.0) Not sure 4(1.1) Number of autistic patients treated per month 1-5 211(65.0) 6-10 49(15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		Special Care Dentist ^b	30 (8.4)
Orthodontist 131 (36.7) Therapist 14 (3.9) Community Dentist 8 (2) Other 42 (11.8)		Dental Nurse	37 (10.4)
Therapist		Hygienist	16 (4.5)
Community Dentist Other 42 (11.8)		Orthodontist	131 (36.7)
Other 42 (11.8) Practice 129 (36.1) Community Practice 68 (19.0) Hours/week patient contact Mean: hours (SD) 19.23 (8.60) Range: hours 2 - 41 Knowingly treated autistic patients Autistic children 123(34.5) Autistic adults 7(2.0) No 7(2.0) Not sure 4(1.1) Number of autistic patients treated per month 1-5 211(65.0) 6-10 49(15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		<u> </u>	14 (3.9)
Practice General Practice General Practice Community Practice Hospital Other Mean: hours (SD) Range: hours Fractice Mean: hours (SD) Range: hours Autistic children Autistic adults Autistic adults Fractice Both children and adults Fractice Autistic patients Fractice Reange: hours Autistic adults Fractice Both children and adults Fractice Fractice Autistic adults Fractice Fractice Fractice Autistic children Fractice Fra		Community Dentist	8 (2)
General Practice 129 (36.1) Community Practice 68 (19.0) Hospital 105 (29.4) Other 54 (15.5) Hours/week patient contact Mean: hours (SD) 19.23 (8.60) Range: hours 2 - 41 Knowingly treated autistic patients Autistic children 123(34.5) Autistic adults 7(2.0) Both children and adults 216(60.5) No 7(2.0) Not sure 4(1.1) Number of autistic patients treated per month 1-5 211(65.0) 6-10 49(15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		Other	42 (11.8)
General Practice 129 (36.1) Community Practice 68 (19.0) Hospital 105 (29.4) Other 54 (15.5) Hours/week patient contact Mean: hours (SD) 19.23 (8.60) Range: hours 2 - 41 Knowingly treated autistic patients Autistic children 123(34.5) Autistic adults 7(2.0) Both children and adults 216(60.5) No 7(2.0) Not sure 4(1.1) Number of autistic patients treated per month 1-5 211(65.0) 6-10 49(15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)	Practice		
Community Practice		General Practice	129 (36.1)
Hospital Other 54 (15.5)		Community Practice	, ,
Hours/week patient contact Mean: hours (SD) 19.23 (8.60) Range: hours 2 - 41		•	105 (29.4)
Mean: hours (SD) 19.23 (8.60) Range: hours 2 - 41 Knowingly treated autistic patients Autistic children 123(34.5) Autistic adults 7(2.0) Both children and adults 216(60.5) No 7(2.0) Not sure 4(1.1) Number of autistic patients treated per month 1-5 211(65.0) 6-10 49(15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) 6.24(10.9) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		-	54 (15.5)
Range: hours 2 - 41	Hours/week patient contact		
Number of autistic patients treated per month		Mean: hours (SD)	19.23 (8.60)
Autistic adults 7(2.0) Both children and adults 216(60.5) No 7(2.0) Not sure 4(1.1) Number of autistic patients treated per month 1-5 211(65.0) 6-10 49(15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		Range: hours	2 - 41
Autistic adults 7(2.0) Both children and adults 216(60.5) No 7(2.0) Not sure 4(1.1) Number of autistic patients treated per month 1-5 211(65.0) 6-10 49(15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)	Knowingly treated autistic patients	Autistic children	123(34.5)
Both children and adults 216(60.5) No	2,7	Autistic adults	, ,
Number of autistic patients treated per month 1-5 211(65.0) 6-10 49(15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		Both children and adults	, ,
Number of autistic patients treated per month 1-5 211(65.0) 6-10 49(15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		No	7(2.0)
per month 1-5 6-10 49(15.2) 11-15 13(4.1) 16-20 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners Paediatric Dentists 14.93(15.6)		Not sure	4(1.1)
6-10 49(15.2) 11-15 13(4.1) 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)	Number of autistic patients treated		
11-15 16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)	per month	1-5	211(65.0)
16-20 20(6.2) 21+ 31(9.5) Mean: number of patients (SD) 6.24(10.9) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		6-10	49(15.2)
21+ 31(9.5) Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		11-15	13(4.1)
Mean: number of patients (SD) General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		16-20	20(6.2)
General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		21+	31(9.5)
General Dental Practitioners 6.24(10.9) Paediatric Dentists 14.93(15.6)		Mean: number of patients (SD)	
Paediatric Dentists 14.93(15.6)		<u> </u>	6.24(10.9)
		Paediatric Dentists	, , ,
		Special Care Dentists	20.62(21.1)

Personal experience of autism

Yes	138(38.7)
No	219(61.3)

Experience working with autistic patients

Nearly all participants reported that they had knowingly treated autistic patients (n= 346; 97%) with most indicating that this experience was with both children and adults on the autism spectrum (60.5%, n=216). Special care dentists (M=20.6) and paediatric dentists (M=14.9), reported seeing many more autistic patients per month than GDP's (M=6.2) (see Table 2). Only 2% respondents said they had never knowingly treated autistic patients (n=7). When asked, in general, if autistic patients are easier or more difficult to treat, the majority (65.9%, n=228) reported that autistic patients are more difficult to treat. Of the respondents who were currently treating or had previously treated autistic patients, 58% (n=207) reported being aware of techniques and resources which can be useful when treating patients on the autism spectrum, while 40.9% (n=146) were not aware of any such techniques. In total, 53.8% (n=192) of dental professionals reported personally using these techniques when treating autistic patients. Some 20.7% (n=74) reported that they may use these techniques and 24.6% (n=88) stated that they did not use any special techniques or resources. More paediatric dentists (84.8%; n=39) and special care dentists (73.3%; n=22) reported using techniques than GDPs (35.1%; n=20).

^a Unless otherwise specified,

^b Note that participants who responded 'Paediatric' or 'Special Care dentist' were not asked to clarify whether they were on a General Dental Council specialist register or not. SD = standard deviation.

Table 2.

Profession	Mean number	Range
	(SD)	
General Dental Practitioner	6.24(10.92)	1-60
Paediatric Dentist	14.93(15.56)	1-70
Special Care Dentist	20.62(21.15)	1-80

Number of autistic patients treated per month, split by type of dental professional

Autism training

Just under half of participants reported having received training on autism (44.7%, n = 156) with 22.1% (n = 79) receiving a specific session dedicated to autism, whilst 21.6% (n = 77) had attended a broader session (e.g. general special needs training). This training was mostly rated as 'extremely useful' or 'moderately useful,' (82.1%, n = 128) with 14.7% (n = 23) reporting it to be 'slightly useful,' and only 3.2% (n = 5) indicating that their training was 'neither useful nor useless' or 'extremely useless'. Paediatric and special care dentists were those most likely to have received training (83% and 80% respectively), compared to approximately 30-38% of the other professional groups.

Knowledge of autism

Table 3 presents each item on the Knowledge of Autism scale and the percentage of dental professionals that correctly answered each item. Overall, the sample showed high knowledge of autism (M=87.8% correct SD=9.01, range=53.28-99.90%). Errors, however, appeared to be systematic, with good knowledge regarding the ability for autistic people to live independently, feel empathy, have sensory differences and be diagnosed in adulthood. The sample performed worse on questions relating to co-morbid mental health conditions, the ability to diagnose autism in females and autistic people's proneness to interpersonal

Dental professionals' confidence in treating autistic patients

violence. A knowledge score was calculated, adjusting for chance responding by using the following equation:

$$R-[W/(n-1)]$$

Where R is the number of right responses, W is the number of wrong responses and n is the number of items in the scale.

Participants' scaled knowledge scores were expressed as a percentage of the total number of questions asked (M=86.99%; SD=9.7; range=0.00-100%). Knowledge scores were not significantly associated with dental professionals' age $r_s(353)$ =-.106, p=.046, how long they had been in practice $r_s(354)$ =-.105, p=.047 or the number of autistic patients they treated a month $r_s(322)$ =.113 p=.043. Dental professionals who had personal experience of autism had higher knowledge scores (Mdn=92.86), than those without (Mdn=85.71), U=12198.500, p=.002. Scaled knowledge scores were also significantly higher for those who had undertaken autism training (Mdn=92.86) than those who had not (Mdn=85.71), U=1330.0, p=.011.

Scaled knowledge scores did not significantly differ between GDPs (Mdn=86.71) and paediatric dentists (Mdn=85.71, U=1292.0, p=.897), GDPs and special care dentists (Mdn=92.86, U=722.0 p=.223) or paediatric and special care dentists (U=579.500 p=.228). It is worth noting, however, that mean knowledge scores are fairly high within all groups (see Table 4).

Table 3. Dentist professionals' accuracy for items on the knowledge of autism scale, n=357

		Number of
		dentists'
		giving a
	Answer	correct
Item	(true/false)	response (%)
People with autism can be interested in social interaction	True	326 (91.3)
Independent living is not possible for autistic people	False	352 (98.6)
People with autism feel no empathy or affection	False	333 (93.3)
A lack of eye contact is necessary for a person to be considered autistic	False	337 (94.4)
Autism cannot be diagnosed in adulthood	False	343 (96.1)
Most people with autism also have intellectual disabilities	False	305 (85.4)
Females are more difficult to diagnose with autism than males	True	192 (53.8)
People with autism always display challenging behaviours	False	338 (94.7)
Autistic people have difficulty with non-literal language and non-verbal communication (e.g. body language and gesturing)	True	316 (88.5)
Additional mental health conditions (e.g. anxiety, depression) are more prevalent in individuals diagnosed with autism than in the general population	True	245 (68.6)
People with autism can show unusual reactions to sensory experiences (e.g. lights, touch, sounds etc)	True	351 (98.3)
Autism is a very rare condition, affecting only 0.05% of the UK population	False	337 (94.4)
Autistic people are more prone to interpersonal violence than non-autistic people	False	244 (68.3)
Change in routine and uncertainty are often upsetting for autistic people	True	356 (99.7)
More than half of people diagnosed with autism do not talk	False	330 (92.4)

Table 4. *Overall knowledge and self-efficacy scores, split by type of dental professional*

	Mean Score		
Profession	(SD)	Range	
Knowledge			
General Dental Practitioner	86.71(10.14)	57.14-100.0	
Paediatric Dentist	85.71(11.95)	50.0-100.0	
Specialist Care Dentist	89.04(10.05)	57.14-100.0	
Self-efficacy			
General Dental Practitioner	4.09(1.30)	1-7	
Paediatric Dentist	5.22(0.87)	2-7	
Specialist Care Dentist	5.40(1.00)	3-7	

Perceived self-efficacy

Despite high knowledge levels being demonstrated, respondents were only somewhat confident in their ability to treat autistic patients (M=4.5, SD=1.2, range=1.00-7.00). Respondents were least confident in their knowledge of relevant local care pathways/services for people on the autism spectrum and were most confident in their ability to treat autistic children. Average self-efficacy scores for each item can be seen in Table 5.

Self-efficacy scores were not significantly related to age r(347)=.081, p=.131,scaled autism knowledge scores r(349)=.098, p=.068, or years in practice r(348)=.109, p=.041. Self-efficacy scores were positively correlated with the number of autistic patients a practitioner treated each month r(318)=.312, p<.001. Greater confidence was demonstrated by dental professionals who had undertaken autism training (M=4.99 SD=1.05) than those who had not (M=4.03, SD=1.11); t(349)=8.20, p<.001. Self-efficacy scores were also higher for respondents who had personal experience of autism (M=4.67, SD=1.23) than those who did not (M=4.34, SD=1.13); t(347)=-2.454) p=.015, however this did not quite reach the adjusted significance level of p= 0.0125.

Significantly less confidence was reported by GDP's (M=4.09 SD=1.30) than paediatric dentists (M=5.22, SD=0.87; t(99)=-4.953, p<.001) and special care dentists (M=5.40 SD=1.00; t(84)=-4.767, p<.001). There was no significant difference between self-efficacy scores for paediatric dentists and special care dentists (t(73)-.812, p=.420; see Table 4).

Table 5.

Mean and mode scores for each item on the self-efficacy scale

	Mean Score		Mode
Item	(SD)	Range	Score
Recognising the signs and symptoms of autism in	4.56 (1.44)	1-7	5
Children			
Recognising the signs and symptoms of autism	4.06 (1.42)	1-7	4
in adults			
Treating autistic children	5.08 (1.28)	1-7	5
Treating autistic adults	4.61 (1.40)	1-7	5
Knowing where to find further information and	4.11 (1.79)	1-7	4
guidance for treating autistic people			
Knowing what adjustments could be made to	4.74 (1.51)	1-7	5
facilitate treatment for autistic people			
Making adjustments in your own practice to facilitate	4.89 (1.41)	1-7	5
treatment for autistic people			
Knowing the relevant local care pathways/services	3.65 (1.84)	1-7	4
for people on the autism spectrum			
Total	4.46 (1.19)		

Scores range from 1 ('not at all confident') to 7 ('extremely confident'). SD= standard deviation.

Qualitative analysis

In total, just under half of the participants (*n*=177; 49.6%) responded to the open question, detailing their views and experiences of working with patients on the autism spectrum, and identifying specific techniques and strategies they found useful. Five main themes emerged from these responses: (1) understanding individual needs, (2) the key role of

communication, (3) the value of autism specific techniques; (4) a conflict between needs and resources and (5) positive and rewarding work (see Figure 1). A full list of themes with example quotes can be found in the supplementary material.

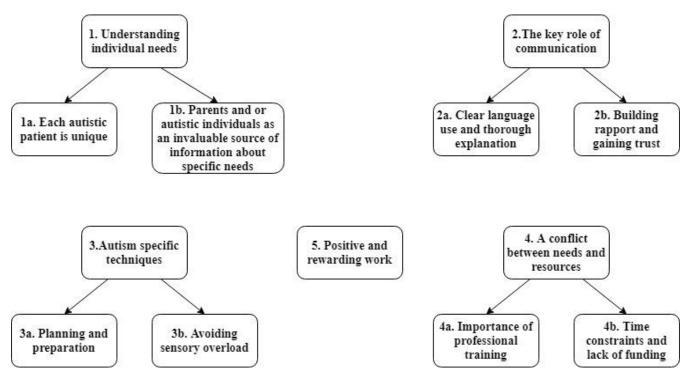


Figure 1. Dental professionals' experiences of working with autistic patients: themes and subthemes.

Understanding individual needs.

A number of respondents highlighted that *each autistic patient is unique* and that to ensure successful treatment, the "individual needs of each patient needs to be taken into consideration, as it affects each client differently (respondent 139)." To establish the nature of these needs, dental professionals recognised *parents and or autistic individuals as an invaluable source of information about specific needs:* "sometimes parents *do* know best how to handle their child, despite being in *my* chair" (respondent 135).

The key role of communication.

Some respondents commented on the need for modified communication, namely adopting the use of *clear language and thorough explanation*. Communication was also necessary in *building rapport and gaining trust* between the dentist and patient. One dentist outlined his team's relationship with an autistic teenager, highlighting that the rapport they had built had positively impacted their communication and "enables her to tell us when she isn't happy and to tell us when her tolerance has been reached" (respondent 17).

Autism-specific techniques.

Besides communicative adaptions, autism-specific techniques were frequently employed to maximise success during treatment. One crucial means of doing so was through *planning and preparation* to make sure that patients encountered minimal surprises during their visit to the surgery. Familiarisation and gradual acclimatisation to the dental surgery, procedures, tools and team were seen as vital for successful treatment. Encouragingly, one surgery mentioned the use of a "storybook walk-through of a visit to the hospital...with photos of every stage and all the staff that the patient will meet on the day...which is personalised with favourite images" (respondent 111). Additionally, 'take-home-packs' were offered to practice with at home, tell-show-do strategies were also employed, and practices made an effort to ensure continuity of staff.

Promisingly, nearly all the dental professionals who responded to the open-ended question were aware of autistic patients' possible sensory differences and detailed how they employed techniques which helped avoid sensory overload. Many respondents reported exerting caution over the use of loud tools and offering apparatus to reduce strain on the senses. Taste preferences were also considered, with dentists explaining that they would "avoid anything with a strong taste," and opt instead for "un-flavoured toothpastes" (respondent 49).

A conflict between needs and resources.

Despite the promising number of adaptions and strategies being employed by dental professionals, there was an evident conflict between understanding that a unique approach is needed to successfully treat autistic patients and having the resources to do so. Many mentioned the *importance of professional training* to ensure a sufficient level of knowledge and understanding of autism, and some professionals pin-pointed a need for attitude change across GDPs. This absence of training means that many relied on advice from colleagues with personal experience in autism to aid their treatment practices.

Dental professionals also commented on *time constraints and lack of funding* as aspects which impaired their ability to provide good quality of treatment to autistic patients. Some dental professionals explained that the complexity and extra time required are not recognised by NHS systems, meaning that often "NHS practitioners treat autistic children and adults by their own good will" (respondent 58) and risk "savage penalties from a target-obsessed system" (respondent 122). Dental professionals also expressed concerns regarding the closure of specialist services due to a lack of funding.

Positive and rewarding work.

Despite the challenges faced by dental professionals noted above, it was clear throughout responses that many dental professionals are working hard to provide a good quality of care to autistic patients. Many respondents left overwhelmingly positive feedback regarding their experiences with autistic patients and there was a running sentiment that they gained personal satisfaction and pride from successfully treating their patients with both knowledge and empathy.

Discussion

Study summary

Dental professionals demonstrated high knowledge levels, but only moderate confidence in treating their autistic patients. Similarly to other literature, both knowledge and self-efficacy were related to autism training. ¹⁸⁻¹⁹ Thus, the lower levels of confidence reported may be explained by the fact that 56% of respondents had never undertaken autism training. Indeed, specialist care dentists and paediatric dentists (whom have undertaken more training and see more autistic patients) showed significantly higher confidence scores than GDPs. Qualitative analysis identified concerns over the lack of training currently available to dental professionals, which may be detrimental to the quality of care they can offer their autistic patients. Other systemic factors were identified as inhibiting good practice, such as a lack of funding for specialist services and time constraints placed on NHS practices to meet targets. Promisingly, despite these obstacles faced by dental professionals, many reported making modifications to practice (e.g. implementing adaptive communication styles, additional planning and extra time) and conveyed largely positive attitudes about doing so, regarding treating those with special health care needs as rewarding and worthwhile work.

Strengths and Limitations

This study yielded numerous positive examples regarding dental professionals' work with autistic patients, however many dental professionals in the current study reported to have a personal connection with autism. This reflects a possible response bias: those with an investment or interest in autism may be more likely to have responded to this survey. If this is the case, then it is possible that the dental professionals already making adaptions are a vocal

minority; the knowledge and confidence levels of dental professionals nationally may be over-represented. Further, dental professionals with specialities (e.g. paediatric dentists) took part in the survey - these professionals are more likely to see autistic patients and to have had specialist training, which potentially could have inflated the confidence levels reported.

Nonetheless, to the authors' knowledge, this is the first study in the UK to detail dental professionals' experiences of treating autistic patients. Further, the study involved a fairly large sample of dental practitioners from various specialities, exceeding that of similar research conducted in the US, ¹⁸⁻¹⁹. As such, it offers an important insight into the additional support needed for UK dental professionals working with autistic patients.

Comparison with existing literature

In the current sample, though participants expressed the need for more training, a higher percentage reported already using aids and making adaptions to current practice than in previous US studies¹⁹. This is encouraging, but may be partially explained by the current study including a considerably higher percentage of dental professionals who have knowingly treated autistic patients compared to previous studies¹⁸⁻²⁰. In addition, similar to previous work with GPs²³, many respondents reported that in the absence of adequate training, they relied on their own personal knowledge and experience of autism or that of their colleagues to aid treatment. Given the variability in needs and preferences of autistic people, an overreliance on personal experiences may lead to dental professionals offering 'one-size-fits-all' accommodations and consequentially producing more discomfort for the patient. It was encouraging, however, to see a number of respondents in the current study flag up an understanding of this individuality, and the need for a tailored approach.

Mirroring the views of parents of autistic children, ⁴ a lack of relevant signposting information for specialist services in the UK was a frustration felt by dental professionals in the current study, pointing to the need for easier access to this information. Indeed a considerable number of respondents reported not being aware of any techniques available to reduce possible discomfort in autistic patients.

Implications for practice

Examining the quality of current autism training for dental professionals could help to improve access to dental care for autistic patients and reduce the reliance on personal experience of autism in treatment. Overall, our findings suggest that the introduction of autism training for dental professionals which aims to enhance confidence, in particular regarding ways in which dental teams can adapt their practices to suit the needs of autistic patients, may help ease anxiety and discomfort currently experienced by some autistic people in general practice settings. Additionally, more easily accessible information regarding signposting avenues should be made available to dental practitioners, such as where to send patients to if they cannot be treated in routine practice. Further, these training initiatives should actively seek to collaborate with autistic individuals and their families, to ensure the dental needs of autistic people are being more effectively met.

References

- Diagnostic and statistical manual of mental disorders. 5th ed. Washington, DC: American Psychiatric Association; 2013.
- 2. Stein L, Polido J, Najera S, Cermak S. Oral Care Experiences and Challenges in Children with Autism Spectrum Disorders. *Paediatric Dentistry*. 2012;34(5):387-391
- 3. Nicolaidis C, Raymaker D, Ashkenazy E, McDonald K, Dern S, Baggs A et al. "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism.* 2015;19(7):824-831.
- 4. Thomas N, Blake S, Morris C, Moles D. Autism and primary care dentistry: parents' experiences of taking children with autism or working diagnosis of autism for dental examinations. *International Journal of Paediatric Dentistry*. 2017;28(2):226-238.
- McKinney C, Nelson T, Scott J, Heaton L, Vaughn M, Lewis C. Predictors of Unmet Dental Need in Children with Autism Spectrum Disorder: Results From a National Sample.
 Academic Pediatrics. 2014;14(6):624-631.
- Delli K, Reichart P, Bornstein M, Livas C. Management of children with autism spectrum disorder in the dental setting: Concerns, behavioural approaches and recommendations.
 Medicina Oral Patología Oral y Cirugia Bucal. 2013:e862-e868.
- 7. Practical Oral Care for People with Autism [Internet]. Bethesda, MD: National Institute of Dental and Craniofacial Research; 2009 [cited 10 January 2019]. Available from: https://www.nidcr.nih.gov/
- 8. Beaton L, Freeman R, Humphris G. Why Are People Afraid of the Dentist? Observations and Explanations. Medical Principles and Practice. 2013;23(4):295-301.
- Annie Thomas D, Shetty D, B. D, Kodgi D. Barriers To Dental Care for Children with Autism Spectrum Disorder- A Pilot Study. IOSR Journal of Dental and Medical Sciences. 2016;15(09):100-105

- 10. Stein Duker L, Henwood B, Bluthenthal R, Juhlin E, Polido J, Cermak S. Parents' perceptions of dental care challenges in male children with autism spectrum disorder: An initial qualitative exploration. *Research in Autism Spectrum Disorders*. 2017;39:63-72.
- 11. Blomqvist M, Dahllöf G, Bejerot S. Experiences of Dental Care and Dental Anxiety in Adults with Autism Spectrum Disorder. *Autism Research and Treatment*. 2014;2014:1-9.
- 12. Isong I, Rao S, Holifield C, Iannuzzi D, Hanson E, Ware J et al. Addressing Dental Fear in Children With Autism Spectrum Disorders. *Clinical Pediatrics*. 2014;53(3):230-237
- Lewis C. Unmet Dental Care Needs Among Children With Special Health Care Needs:
 Implications for the Medical Home. *Pediatrics*. 2005;116(3):e426-e431.
- 14. Lai B, Milano M, Roberts M, Hooper S. Unmet Dental Needs and Barriers to Dental Care Among Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*. 2012;42(7):1294-1303.
- El-Meligy, O., Maashi, M., Al-Mushayt, A., Al-Nowaiser, A. and Al-Mubark, S. (2016). The
 Effect of Full-Mouth Rehabilitation on Oral Health-Related Quality of Life for Children with
 Special Health Care Needs. *Journal of Clinical Pediatric Dentistry*, 40(1), pp.53-61
- 16. da Silva S, Gimenez T, Souza R, Mello-Moura A, Raggio D, Morimoto S et al. Oral health status of children and young adults with autism spectrum disorders: systematic review and meta-analysis. International Journal of Paediatric Dentistry. 2016;27(5):388-398.
- 17. Brickhouse T, Farrington F, Best A, Ellsworth C. Barriers to dental care for children in Virginia with autism spectrum disorders. Journal of Dentistry for Children. 2009;76(3):188-193
- 18. Dao L, Zwetchkenbaum S, Inglehart M. General dentists and special needs patients: does dental education matter?. *Journal of Dental Education*. 2005;69(10):1107-1115.
- Weil T, Inglehart M. Dental Education and Dentists' Attitudes and Behavior Concerning
 Patients with Autism. Journal Of Dental Education. 2010;74(12):1294-1307

- 20. Alkahtani, Z., Stark, P., Loo, C., Wright, W. and Morgan, J. (2014). Saudi and U.S. dental student attitudes toward treating individuals with developmental disabilities. Journal of Dental Education, 78(8), pp.1145-115
- Nicolaidis C, Kripke C, Raymaker D. Primary Care for Adults on the Autism Spectrum.
 Medical Clinics of North America. 2014;98(5):1169-1191.
- 22. Guide for Commissioning Special Care Dentistry. NHS England; 2015.
- 23. Unigwe S, Buckley C, Crane L, Kenny L, Remington A, Pellicano E. GPs' confidence in caring for their patients on the autism spectrum: an online self-report study. British Journal of General Practice. 2017;67(659):e445-e452.
- 24. Bandura A. Self-efficacy: The Exercise of Control. New York: W.H. Freeman; 1997.
- IBM Corp. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.
 Released 2017.
- 26. Steckler A, McLeroy K, Goodman R, Bird S, McCormick L. Toward Integrating Qualitative and Quantitative Methods: An Introduction. Health Education Quarterly. 1992;19(1):1-8.
- 27. Bankauskaite V, Saarelma O. Why are people dissatisfied with medical care services in Lithuania? A qualitative study using responses to open-ended questions.

 International Journal for Quality in Health Care. 2003;15(1):23-29
- 28. Boulton M, Fitzpatrick R, Swinburn C. Qualitative research in health care: II. A structured review and evaluation of studies. Journal of Evaluation in Clinical Practice. 1996;2(3):171-179.
- 29. George R, Crane L, Bingham A, Pophale C, Remington A. Legal professionals' knowledge and experience of autistic adults in the family justice system. Journal of Social Welfare and Family Law. 2018;40(1):78-97.
- 30. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3(2):77-101.

Dental professionals' confidence in treating autistic patients

31. Patton M. Qualitative evaluation and research methods. 2nd ed. Newbury Park: CA: Sage; 1990.