



UNIVERSITY *of the*
WESTERN CAPE

Oral Health Practices and Challenges Facing Parents of Autistic Children in the Western Cape

**Mini-thesis submitted in partial fulfilment of the requirements for the
degree of MSc in Paediatric Dentistry.**

Dr Rayan Omer

Student ID: 3914178

Supervisor: Professor Nadia Mohamed

Co-supervisor: Dr Craig Peck

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ABSTRACT

Background

Autism, as a neurodevelopmental disorder, is typically characterized by impaired social interaction, limited interests and repetitive patterns of stereotypical behaviours. Periodontal status and oral hygiene practices are found to be deficient in autistic children. This is attributed to challenges in oral health practices at home in addition to the burden of unmet dental needs due to challenges in providing treatment to these children.

Aim

The aim of this research was to identify and understand parental challenges regarding the oral health practices of autistic patients at home and to identify the barriers related to dental treatment of Autism Spectrum Disorder (ASD) children based on their child's experiences in the dental office.

Methods

A cross-sectional study included 54 parents of Autism Spectrum Disorder (ASD) children attending autism support group centres in the Western Cape. Data collection was completed through structured online questionnaires distributed among the parents. The questionnaire was comprised of four sections, namely socio-demographics; medical history and pharmacotherapeutic treatment of the child; oral health challenges faced by parents at home, and finally, oral health challenges in the dental clinic.

Results

Autistic children are dependent on their parents for daily routine oral hygiene. Assistance or supervision during tooth brushing was reported by 59% of the parents. Oral habits such as thumb sucking were reported in almost half of the children. In the dental clinic, 58% of the parents described the child's behaviour as uncooperative and 33.3% rated their child's last dental visit as being negative. The majority of parents reported irregular visits to the dentist with extractions being the most commonly performed dental procedure.

Conclusion

The findings of this study suggest that parents should actively assist their children with brushing, flossing and other oral hygiene methods. Whether it was due to a lack of knowledge or to difficulty to implement, the absence of flossing was particularly striking among this cohort of children.

In the dental clinic, uncooperative behaviour of children with Autism Spectrum Disorder (ASD) is the main barrier to dental treatment. Dentists should schedule appointments in the early morning, ideally with the same dentist, and patient waiting times should be reduced. Parents also reported difficulties in finding a competent dentist and an appealing clinical environment. Options for treatment under sedation or General Anaesthesia are more readily acceptable among parents of Autistic children and can serve as viable treatment options for uncooperative children.

Keywords

Oral Health; Autistic children; ASD children; Challenges; Parents



DECLARATION

I, the undersigned, Rayan Omer, hereby declare that the work contained in this thesis entitled “Oral Health Practices and Challenges Facing Parents of Autistic Children in the Western Cape”, is my original work and has not previously been submitted (in its entirety or in any part thereof) at any university for any degree or examination purposes.

Rayan Omer Saeed

April 2022



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I wish to show appreciation and deepest gratitude to my supervisor Prof. N. Mohamed for her continuous guidance throughout this project. This work could have not been completed without Prof. Mohamed's valuable input. More importantly, you have taught me persistence, dedication and to never settle for anything less than perfection. You have managed to guide me to my full potential and for that, I will remain grateful.

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Finally, I would like to thank Autism Western Cape for granting me access to their support groups. Moreover, thank you to the participants- the powerful parents who made this project come true.



DEDICATION

To my parents,

For their endless support and encouragement. You always ensured I get the best of opportunities. Your efforts have given me the key to unlock the doors to the world, and beyond.

To my sisters and brother,

Who have given me the drive to finish this work with enthusiasm and dedication.

To my beloved husband,

Through times hard and fraught with turbulence, you patiently stood by.

To my dear friends,

Your faith, love and support has shed light through the darkest of days.

Thank you.

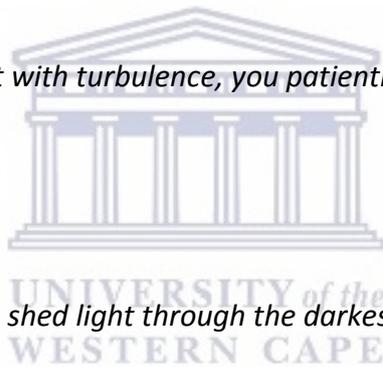


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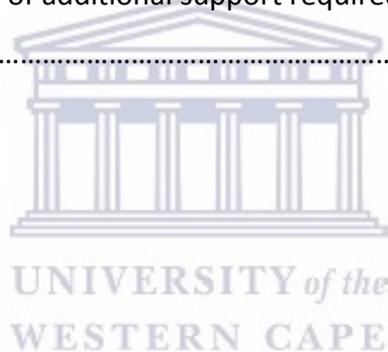
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LIST OF ABBREVIATIONS

AAPD	American Academy of Paediatric Dentists
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
BMREC	Biomedical Research Ethics Committee
BT	Behaviour Therapy
DMFT	Decayed, Missing due to caries or Filled teeth
GA	General Anaesthesia
ID	Intellectual Disability
IQR	Interquartile Range
PDD-NOS	Pervasive developmental Disorders not Otherwise Specified
SES	Socioeconomic Status
SIB	Self-injurious Behaviour
UAE	United Arab Emirates



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CHAPTER ONE

INTRODUCTION AND LITERATURE REVIEW

Introduction

Available data regarding the prevalence of autism in Sub-Saharan Africa is strikingly scarce (Bakare & Munir, 2011). In South Africa, no different than elsewhere in Sub-Saharan Africa, epidemiological surveys attempting to quantify the prevalence of autism are not available (Springer *et al.*, 2013). However, global estimates of autism indicate that 62 in every 10 000 children are born with autism worldwide (Elsabbagh *et al.*, 2012). This equates to one in every 170 children, which suggests that the probability exists that a child with autism is born every hour. It is reported that children with autism have difficulty establishing communication, whether verbal or non-verbal, are prone to repetitive behaviours, have diminished social skills and have a narrow range of interests (Charles, 2010). Research has widely described that children with autism spectrum disorders behave and communicate differently and that every child has their own unique interactive characteristics and treatment needs (Keen *et al.*, 2016). Several studies have described an increase in gum disease and poor periodontal status in autistic children when compared to non-autistic children (DeMattei, 2007; Fakroon *et al.*, 2015). It was concluded that several challenges to oral health practices exist at home, which contribute to both caries and periodontal disease in autistic children (Stein *et al.*, 2012a). In addition, in the United States of America, a secondary analysis of data from the National Survey of Children with Special Health Care Needs, revealed that behavioural and communication barriers were linked to significantly higher unmet dental needs associated with Autism Spectrum Disorder (ASD) patients (McKinney *et al.*, 2014). Parents of these children also frequently rate their children's experience in the dental office as being negative (Mansoor *et al.*, 2018).

Literature Review

1.1. Introduction

The American Psychiatric Association (2013) defines autism as a neurodevelopmental disorder, typically characterized by impaired social interaction, limited interests and repetitive patterns of stereotypical behaviours such as repetitive body movements. Autism is one of the Autism Spectrum Disorders, alongside Asperger's syndrome and other pervasive developmental disorders not otherwise specified (American Psychiatric Association, 2013).

1.2. Prevalence of Autism Spectrum Disorder

The prevalence of autism seems to be increasing worldwide, and evidence suggests it is not affected by geographic, ethnic or cultural variants. Proof of this is however very limited (Elsabbagh *et al.*, 2012). In the USA, The Centre for Disease Control and Prevention (2018) reported the prevalence to be one in every 59 eight-year-old children displaying some degree of autism. This demonstrates a 15% increase compared to the prevalence reported in 2016 (Baio *et al.*, 2014). ASD is consistently observed to be four times more common in males than females (Fombonne, 2009) and socioeconomic status is not significantly associated with increased risk of autism (Larsson *et al.*, 2005).

Most of our current understanding and knowledge about autism is based on information and data from western countries. To date, studies from Sub-Saharan Africa have attempted to identify the existence of ASD, but were not comprehensive enough to be considered representative epidemiological studies (Ametepee & Chitiyo, 2009). A literature review on autism in Africa conducted by Bakare & Munir (2011), concluded that population-based surveys were either unavailable or preliminary. This review found 12 relevant reports with only two epidemiological surveys, even though this region has a population of nearly 1 billion, 40% of whom are children. A study conducted throughout nine Arabic-speaking countries in Northern Africa, reported the prevalence of autism to range between 11.5% and 33.6% in Tunisia and Egypt respectively (Seif Eldin *et al.*, 2008).

In South Africa specifically, the prevalence of ASD has not been well documented (Springer *et al.*, 2013). A ten-year survey from 1996 to 2005 in a clinic for children with developmental delay in Johannesburg, reported an 8.2% increase in children who presented with autistic

features (Jacklin, 2006). Springer *et al.* (2013) conducted a study at Cape Town's Tygerberg Hospital (a tertiary level Healthcare Centre) and reported that ASD children mostly presented with severe language impairment, comorbidities and complex autism, which required medical, educational and social support.

1.3. Aetiology, diagnosis and management of autistic disorders

To date, there is no proven aetiology of autism (Currenti, 2010). Historically, Measles, Mumps and Rubella vaccinations were considered a possible aetiological factor for autism (Wakefield *et al.*, 1998), but this research has been rejected due to inferior and unethical methodological approaches (Rao & Andrade, 2011). Possible genetic causes of autism have been extensively researched (Geschwind & State, 2015). Moreover, scientists have argued for decades that other possible causes such as maternal infections with German measles, intake of antiepileptic drugs and environmental exposure to heavy metals and biphenyls (Sealey *et al.*, 2016), could increase the likelihood of having a child with autism. However, there is insufficient evidence to support these claims (Gardener *et al.*, 2009). Currently, consensus has been reached which highlights that the way forward should rather be to focus on a combination of environmental and genetic factors as aetiological determinants of autism (Tordjman *et al.*, 2014).

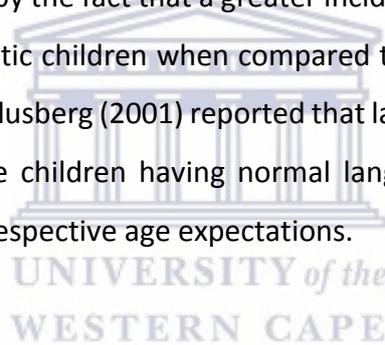
A diagnosis of autism is usually established within the first three years of life, although in some instances as early as 18 months (Lord *et al.*, 2006). Bakare & Munir (2013) reported, however, that children in Africa were diagnosed with ASD at a late age and more commonly presented with intellectual disability and delay in language development.

There is currently no cure for autism. Behavioural and psycho-educational modalities have been adopted in an attempt to facilitate relative improvement in communication abilities (Francis, 2005). Psychotropic drugs (such as anti-psychotic and anti-depressive drugs) are often prescribed for aggression and hyperactivity (Francis, 2005), and often result in side effects such as xerostomia, sialadenitis, dysphagia and stomatitis (Chandrashekar & Bommangoudar, 2018).

1.4. ASD-associated impairments and comorbidities

Patients with ASD display a great variability in the severity of the disease manifestations, its outcomes and adaptive capacity. Matson and Shoemaker (2009) found considerable overlap between Intellectual Disability (ID) and autism, with no agreement in the literature as to the prevalence of ID among ASD patients. However, the diagnosis of ID along with ASD is considered to be a poor prognostic marker. Several comorbidities have been associated with autism, the most prevalent being seizures, gastrointestinal problems, sleep disturbances and depression, resulting in complicated treatment needs (Charles, 2010).

The psycho-pathology of autistic children reveals that they are more likely to suffer from attention deficit, hyperactivity and destructive behaviours such as repetitive head-banging (Brereton *et al.*, 2006). Because these children present with communication disorders and language disabilities, diagnosing them with mental disorders is challenging (DeFilippis, 2018). This is additionally confounded by the fact that a greater incidence of anxiety and depression has been demonstrated in autistic children when compared to non-autistic children (Kim *et al.*, 2000). Kjelgaard and Tager-Flusberg (2001) reported that language impairments displayed great heterogeneity, with some children having normal language skills while others have levels significantly below their respective age expectations.



1.5. The impact of ASD on families and caregivers

In a study conducted by Howlin *et al.* (2004), only a few ASD patients were regarded as independent, with the majority being highly dependent on their families and social services, even after adulthood. The demanding and persistent lifelong care that needs to be provided to autistic children and adults, places a burden on the everyday life of their caregivers. Primary caregivers of autistic children report physical health problems, physiological distress, lower family-related quality of life and difficulties completing their own tasks along with the daily activities of the individual they have to care for (Bromley *et al.*, 2004; Hoefman *et al.*, 2014). Delayed language development in autistic children was the most significant factor associated with high caregiver burden due to difficulties in communication (Baykal *et al.*, 2019). Saunders *et al.* (2015) reported that half of the caregivers in families having children with a combination of ASD and intellectual disability, suffered financial difficulty and had to stop work to take care of the child.

1.6. Oral health status and practices in individuals with ASD

Despite the increase in the number of children with special needs, specifically children with sensory disorders, recognition of the importance of their oral health is still limited (Bartolomé-Villar *et al.*, 2016). Although oral health status (particularly caries) in this group has been studied frequently, it appears that no consensus regarding the caries experience has been reached in the literature. A systematic review conducted by Bartolomé-Villar *et al.* (2016) concluded that no significant difference was noted in terms of caries prevalence among ASD children when compared with non-ASD children. Similar results were reported by Orellana *et al.* (2012). Cross-sectional case control studies have reported lower caries incidence amongst children with ASD compared to medically fit children (Du *et al.*, 2015b; Fakroon *et al.*, 2015). On the contrary, research has reported a higher mean decayed, missing due to caries or filled teeth (DMFT) in autistic children (Richa *et al.*, 2014). Nevertheless, a higher prevalence of caries in permanent teeth in comparison to primary teeth was reported (Jaber, 2011).

Dietary habits largely affect the development of caries. Most children with ASD prefer soft foods, foods high in sugar content, soft drinks as well as snacking in-between meals (Marshall *et al.*, 2010; Murshid, 2014). Sweets were commonly given to them by their parents as a reward (Marshall *et al.*, 2010). In addition, autistic children tend to pouch food in their mouths, due to poor tongue coordination (Jaber, 2011).

Periodontal status and oral hygiene practices are found to be deficient and poorer in autistic children, with higher plaque and gingival indices which necessitates a greater need for professional scaling (DeMattei, 2007; Jaber, 2011; Fakroon *et al.*, 2015; Da Silva *et al.*, 2017). Moreover, xerostomia (due to medications) increases the risk of caries and periodontal disease in ASD patients (Lu *et al.*, 2013). The poor periodontal status can be attributed to difficulties with oral hygiene practices, due to reduced manual dexterity and non-compliance with brushing (Jaber, 2011).

Stein *et al.* (2012b) reported that 50% of children with autism require some or complete physical assistance during brushing. Sensory sensitivity also presents a challenge for performing daily brushing activities at home and completing dental treatment, due to the inability of the child to tolerate drilling sounds, bright lights and instrumentation inside the oral cavity (Stein *et al.*, 2012a). Parents of ASD children frequently reported that their children

resisted brushing due to disliking the feeling of the brush or the toothpaste (Mansoor *et al.*, 2018). In addition, some parents reported that their preschool children were scared of tooth-brushing and could not keep still, making brushing a very difficult task (Du *et al.*, 2019).

Studies on the effect of behaviour-therapy on oral hygiene practices at home is lacking. However, the collaboration between dentists and occupational therapists has been reported to be beneficial (Como *et al.*, 2021). Occupational therapists provide ASD-specific strategies, such as desensitization and social stories, to help reduce some barriers encountered with ASD children in the clinic (Como *et al.*, 2021).

Children with ASD exhibit bruxism more frequently, resulting in tooth loss due to attrition involving the dentine (Orellana *et al.*, 2012; Du *et al.*, 2015b; Bartolomé-Villar *et al.*, 2016). Self-inflicted trauma and injuries are well recognised in adult ASD patients, particularly on the hands, arms, head and neck (Orellana *et al.*, 2012). A study conducted in India by Richa *et al.*, (2014), observed that lip-biting and hair-pulling were strongly associated with ASD when compared with a non-ASD control group.

1.7. Unmet dental needs and challenges to oral health care

Lai *et al.* (2012) reported that 12% of children with autism still had unmet dental treatment needs, despite the majority having been to the dentist in the previous six months. A similar study conducted by Naidoo and Singh (2018) in South Africa, assessed the oral health status in children with autism aged between 7 and 14 years in KwaZulu-Natal. It was concluded that, despite a low DMFT score, a significant proportion of primary molars contributed to the decay component. In addition, no filled teeth were recorded, indicating minimal restorative treatment was done, resulting in unmet treatment needs. The barriers reported by the authors in both of these studies included the difficult behaviour of the child, inability to find a dentist willing to provide treatment and the cost of dental care (Lai *et al.*, 2012; Naidoo & Singh, 2018). Murshid (2014), in a sample of 450 parents of children with autism in Saudi Arabia, reported that half of the children had no previous exposure to dental treatment and of those who received treatment, 25% of them underwent general anaesthesia due to the extensive and lengthy procedures needed. In the United Arab Emirates (UAE), Jaber (2011) found that a higher percentage of patients with ASD (30%) had substantially greater unmet dental needs and required comprehensive dental treatment under general anaesthesia due

to difficult behavioural management. The continuous development of dental caries and poor oral hygiene practices negatively impacts on the oral health-related quality of life of children with autism (Richa *et al.*, 2014).

A recent study conducted in Dubai, investigating the challenges facing children with ASD, assessed both barriers at home and in clinics through questionnaires directed at their parents. The study reported the need for assistance during brushing and highlighted the most common barriers to oral hygiene practices, which included a dislike of toothpaste, amongst others (Mansoor *et al.*, 2018). Similar findings were reported by Stein *et al.* (2012b), who found, in addition to difficulties with daily oral care at home, ASD individuals also reportedly brushed less often per week when compared to their non-autistic peers.

In the dental office, 37% of parents with children who had ASD described their children's last experience as negative and admittedly reported that their child's behaviour discouraged them from visiting the dentist (Mansoor *et al.*, 2018). Oral defensiveness is a common condition among ASD children. It usually refers to tactile, visual and auditory hypersensitivity to the area surrounding and inside the oral cavity (Spira & Kupietzky, 2005). This extreme sensory sensitivity of these patients to their surroundings, make dental appointments more difficult for children. In addition to uncooperative behaviour, parents report these sensitivities more frequently during the dental visit (Stein *et al.*, 2012b). Moreover, a quarter of parents in the Stein *et al.* study (2012b) stated that they had previously encountered a dentist who refused to provide dental treatment for their child. According to these parents, the most common reason given by the dentists was that they felt they were inadequately trained for working on children with special needs.

1.8. Cooperation of autistic children with dental treatment

Du *et al.* (2015a) concluded that children with higher cognitive functioning and fewer challenging behaviours have a greater probability of successfully cooperating with dental screening procedures. The challenge still remains to determine which behavioural management interventions could aid the dentist during treatment. Successful child management techniques for patients with ASD in the clinic were reviewed by Chandrashekar and Bommangoudar (2018). The researchers recommended short appointment waiting times, slight modifications to the techniques of "tell, show, do" using pictures, positive

reinforcement, social stories and discouraging the application of aversive techniques such as hand-over-mouth. Additionally, repetitive behaviours like planning appointments on the same day of the week, at the same time and with the same dentist could all prove beneficial (Klein & Nowak, 1998).

Social stories are particularly helpful before dental appointments (Gray, 2010). Such a tool utilises visual aids to provide guidance for the proper responses for social situations that an autistic child may encounter. The concept relies on the fact that ASD children communicate better through pictures than words (Bäckman & Pilebro, 1999). However, healthcare providers argue that human and time resources present two barriers which restrict the application of non-pharmacological techniques (Klein & Nowak 1998).

An in-depth understanding of these challenges will enable the dental fraternity to establish appropriate guidelines to assist parents and help improve the oral health of their autistic children. The present research thus aims to investigate the oral health practices and challenges facing the children with autism from the perspective of their parents.



CHAPTER TWO

RESEARCH METHODOLOGY

2.1. Aim

The research aimed to investigate the perspectives of parents with autistic children with regards to oral health practices and challenges.

2.2. Objectives

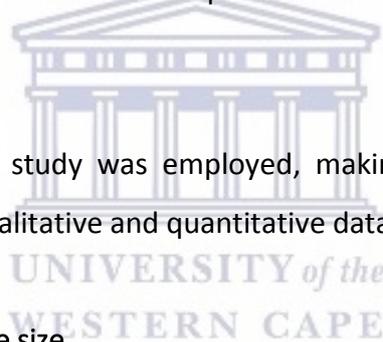
2.2.1. To identify the oral health practices of autistic patients.

2.2.2. To identify and understand the parental challenges regarding the oral health practices of their autistic children at home.

2.2.3. To identify the barriers related to dental treatment as reported by the parents of autistic children based on their child's experiences in the dental office.

2.3. Study design

An exploratory, cross-sectional study was employed, making use of a structured online questionnaire to gather both qualitative and quantitative data.



2.4. Study population and sample size

Convenience sampling of parents with autistic children attending autism support group centres in the Western Cape was conducted. Seven support groups are located in the Western Cape, which includes a total of approximately 100 parents. As confirmed by the statistician, a sample size of 60 participants was deemed sufficient.

2.5. Inclusion Criteria

The inclusion criteria were parents whose children were diagnosed with autism spectrum disorder and who provided informed consent to participate in the study. All children with ASD were below 12 years of age.

2.6. Exclusion criteria

Parents who were not the primary caregivers were excluded from the study.

2.7. Data collection

Due to COVID-19 and the inability to conduct face-to-face interviews, data collection was conducted online using a structured questionnaire on Google Forms. The link was distributed to the participants by Autism Western Cape via email. The questionnaire included both closed- and open-ended questions to elicit information-rich data. As English is the medium of communication used during monthly support group meetings, translation of the questionnaire was not required. The questionnaire was tested on a sample of participants before the commencement of the main study to ensure clarity of the questions.

2.8. Questionnaire

The structured questionnaire was composed of 58 items, organised into four constructs (Appendix 2). The first construct identified the socio-demographic characteristics of the child (including age, sex and the number of siblings in the household), as well as the socio-demographic characteristics of the parents (highest level of formal education, marital status and monthly income). The second construct contained questions which intended to elicit information on the child's medical history, accompanying medical conditions, medications, self-injurious behaviour and the history of any behavioural therapy experienced / received. The third and fourth constructs were comprised of questions relating to oral hygiene practices and the accompanying challenges at home and in the dental clinic respectively, as described previously by Stein *et al.* (2012), Capozza and Bimstein (2012) and Mansoor *et al.* (2018). Questions in the third construct were related to the oral hygiene practices and directed towards possible challenges in terms of brushing, flossing, the use of mouthwash and presence of oral habits. Questions in the fourth construct were related to autistic children's experiences and behaviour in the dental office, challenges in terms of cooperation with dental treatment, and their experiences of pharmacological and non-pharmacological behaviour management.

The questions aimed to identify the challenges and then quantify the probability of their occurrence within this group; hence the use of both qualitative and quantitative analytic methods. Some questions were dichotomous (i.e. yes / no) or made use of a Likert scale, while others were open-ended, to probe for greater depth and generate more richness from the data.

2.9. Data analysis

Statistical analysis was conducted using StataCorp. (2021). Stata Statistical Software: Release 17. College Station, TX: StataCorp LLC. All categorical data were displayed as frequencies and percentages. All associations were performed using a Chi-squared test of association or a Fisher's exact test if the cell frequencies were less than five. The tests were deemed statistically significant with $p < 0.05$.

For open-ended questions, thematic analysis was conducted on the qualitative responses using the method as described by Braun and Clarke (2012). Data extracts were coded and themes generated, reviewed and analysed in an iterative manner to ensure rigour of the data set generated.

2.10. Budget

None. All data was collected online.

2.11. Ethical considerations and data protection

The study was approved by the Research Committee of the University of the Western Cape, and (BMREC) Biomedical Research Ethics Committee (BM19/7/11) (Appendix 1). Alpha-numeric codes (rather than names) were allocated to participants to ensure confidentiality. Therefore, no de-identification of the collected data was needed. Raw data was stored in an Excel spreadsheet on a password-protected computer. All records will be stored for five years following collection, with only the principal researcher having access to it. The records will be disposed of after five years.

At the beginning of the online questionnaire, each parent was provided with information explaining the purpose of the research on the Google Form. In addition, the online form emphasised voluntary participation and autonomy of the information gathered. Completion of the questionnaire by the parent was considered to be a sign of consent. If parents did not consent, they did not carry on with the questionnaire. Contact details of the principal investigator were included and dental advice was still provided if sought, regardless of whether parents participated in the study or not.

CHAPTER THREE

RESULTS

A total of 54 parents (all of whom had a child who was diagnosed with ASD), participated in the study. Results will be displayed as tables and graphs under the various subheadings.

3.1. Socio-demographics

Table 3.1.1: Demographics of the study participants (N = 54).

Sociodemographic variables	Categories	N (%)
Relationship to the child	Biological parent	51 (94.4%)
	Adoptive parent	3 (5.6%)
Parental age	Below 40 years	19 (35.2%)
	Above 40 years	35 (64.8%)
Age of the child	2 - 4 years	6 (11.1%)
	5 - 7 years	17 (31.5%)
	8 - 10 years	11 (20.4%)
	11- 12 years	20 (37%)
Sex of the child	Female	8 (14.8%)
	Male	46 (85.2%)
Sibling(s) with autism	Yes	7 (13%)
	No	47 (87%)
Marital Status	Married / cohabiting	40 (74.1%)
	Divorced / single	14 (25.9%)
Employment status	Employed	31 (57.4%)
	Unemployed	23 (42.6%)
Highest level of Education (Parent)	School education	23 (42.6%)
	Tertiary education / above	31 (57.4%)
Monthly household income	Below R5 000	15 (27.8%)
	R5 000 - R9 999	11 (20.4%)
	Above R10 000	28 (51.8%)

3.2. Medical History

Table 3.2.1: Medical information, medication intake and self-injurious behaviour of autistic children as reported by their parents.

Variables	Categories	N (%)
Medical conditions besides autism	Yes	21 (38.9%)
	No	33 (61.1%)
Medications for autism	Yes	21 (38.9%)
	No	33 (61.1%)
Previous Behaviour Therapy	Yes	22 (40.7%)
	No	32 (59.3%)
Self-injurious behaviour	Yes	11 (20.4%)
	No	43 (79.6%)

The results indicate that the median age for autism diagnosis was three years. The Interquartile range (IQR) was 3 to 5, while the median age for time spent in behaviour therapy by the children was 1.5 years (IQR: 0.75 to 2.5).

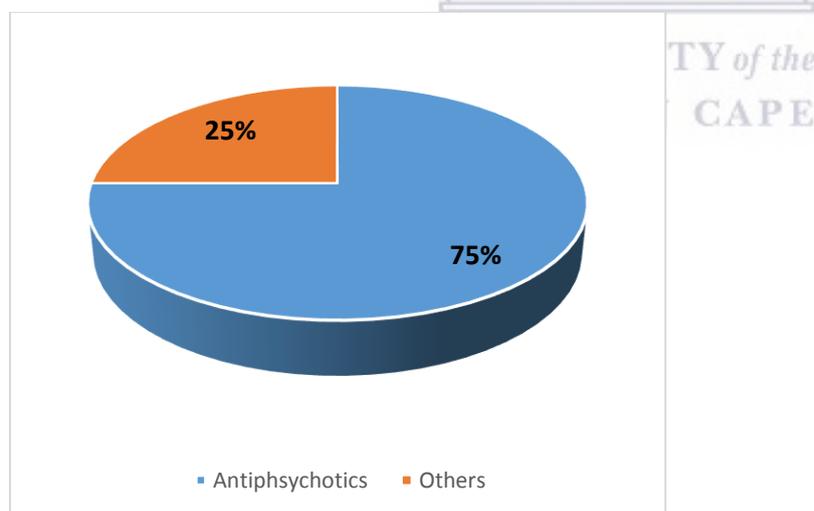


Figure 3.2.1: Most commonly reported medications among ASD children receiving medications.

3.3. Challenges to oral healthcare practices at home

Table 3.3.1: Challenges reported by parents in relation to brushing, flossing and oral habits of their autistic children.

Variable	Categories	N (%)
Does the child clean their teeth regularly?	No	11 (20.4%)
	Yes, alone	11 (20.4%)
	Yes, assisted	21 (38.8%)
	Yes, supervised	11 (20.4%)
Frequency of brushing per day	None	6 (11.1%)
	Once	29 (53.7%)
	Twice/ more	19 (35.2%)
Is brushing easy to do? (for those parents who assist/supervise brushing)	Yes	2 (6.3%)
	No	30 (93.7%)
Oral hygiene method used	Cloth only	7 (13%)
	Brush/ toothpaste	47 (87%)
Previously tried electric toothbrush	Yes	25 (46.3%)
	No	29 (53.7%)
Child more cooperative with electric toothbrush (for those who use electric toothbrushes)	Yes	12 (48%)
	No	13 (52%)
Does the child swallow toothpaste	Yes	23 (42.6%)
	No	31 (57.4%)
Does the child / parent floss	Yes	5 (9.3%)
	No	49 (90.7%)
Other methods of plaque control used	Yes	18 (33.3%)
	No	36 (66.7%)
Tried using sugar-free gum in the past	Yes	8 (14.8%)
	No	46 (85.2%)
Are oral habits exhibited	Yes	24 (44.4%)
	No	30 (55.6%)
Has the parent tried to stop the habit (of those who reported habits)	Yes	12 (50%)
	No	12 (50%)

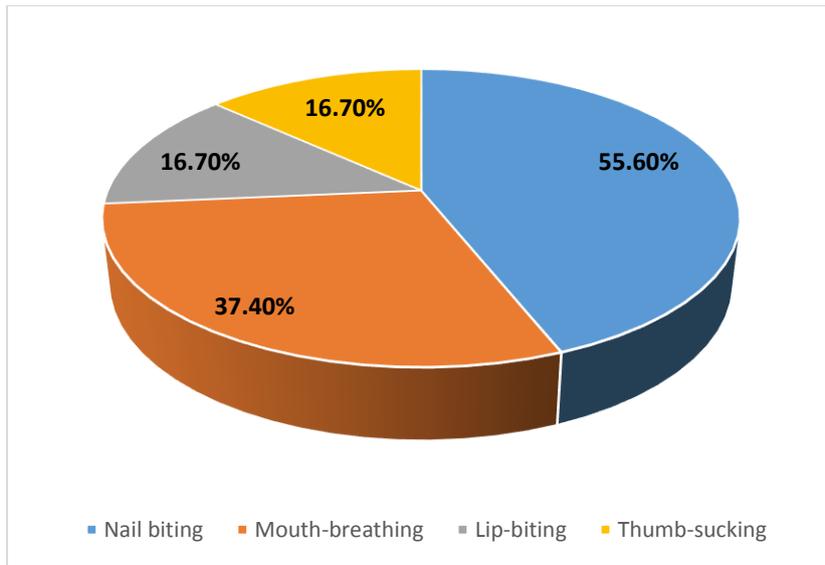


Figure 3.3.1: Distribution of oral habits reported among ASD children (n=24).

Table 3.3.2: The association between the sex of the child and brushing habits.

Sex of the child	Brushing habits				Total N = 54	p value
	No (n = 11)	Yes, alone (n = 11)	Yes, assisted by the parent (n = 21)	Yes, supervised by the parent (n = 11)		
Female	0 (0%)	1 (12.5%)	3 (37.5%)	4 (50.00%)	8 (14.8%)	0.137
Male	11 (23.9%)	10 (21.8%)	18 (39.1%)	7 (15.2%)	46 (85.2%)	

Table 3.3.3: The association between the parental education status and brushing habits of their autistic child.

Highest level of parental education	Brushing Habits				Total N = 54	p value
	No (n = 11)	Yes, alone (n = 11)	Yes, assisted by the parent (n = 21)	Yes, supervised by the parent (n = 11)		
School education only	8 (34.8%)	6 (26.1%)	7 (30.4%)	2 (8.7%)	23 (42.6%)	0.043
Tertiary education and above	3 (9.7%)	5 (16.1%)	14 (45.2%)	9 (29%)	31 (57.4%)	

Table 3.3.4: The association between the child's age and whether the parents have tried other methods of plaque control at home.

Child's age	Other methods of plaque control used		Total (N = 54)	p value
	Yes (n = 18)	No (n = 36)		
2 - 4 years	1 (16.7%)	5 (83.3%)	6 (11.1%)	0.004
5 - 7 years	1 (5.9%)	16 (94.1%)	17 (31.5%)	
8 - 10 years	7 (63.6%)	4 (36.4%)	11 (20.4%)	
Above 10 years	9 (45%)	11 (55%)	20 (37%)	

Table 3.3.5: The association between parental marital status, and whether the parents have tried other methods of plaque control for their child (e.g. mouthwash).

Marital status	Other methods of plaque control		Total (N = 54)	p value
	Yes (n = 18)	No (n = 36)		
Married / cohabitating	10 (25%)	30 (75%)	40 (74%)	0.028
Single / divorced	8 (57.1%)	6 (42.9%)	14 (26%)	

Table 3.3.6: The association between parental education status, and whether they have tried using an electric toothbrush to clean their autistic child’s teeth.

Highest level of education obtained	Usage of electric toothbrush		Total (N = 54)	p value
	Yes (n = 25)	No (n = 29)		
School education only	7 (30.4%)	16 (69.6%)	23 (42.6%)	0.044
Tertiary education and above	18 (58.1%)	13 (41.9%)	31 (57.4%)	

3.4. Challenges to oral health care in the clinic

3.4.1. Behaviour and cooperation

Table 3.4.1: Challenges faced by parents of autistic children regarding dental treatment in the clinics.

Variable	Categories	N (%)
Does your child’s behaviour discourage you from visiting the dentist?	Yes	33 (61.1%)
	No	21 (38.9%)
Has your child ever been physically restrained to complete dental treatment?	Yes	15 (27.8%)
	No	39 (72.2%)
Has your child previously undergone dental treatment under general anaesthesia/ sedation?	Yes	19 (35.2%)
	No	35 (64.8%)
Do you prefer that your child’s dental treatment be completed under general anaesthesia/ sedation?	Yes	40 (74.1%)
	No	14 (25.9%)

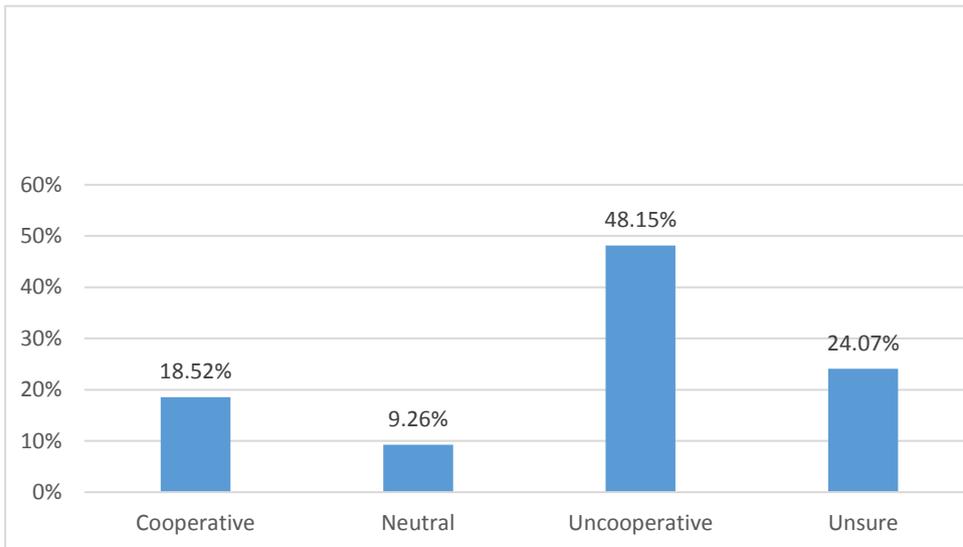


Figure 3.4 1: Parental description of the child's usual response at the dentist.

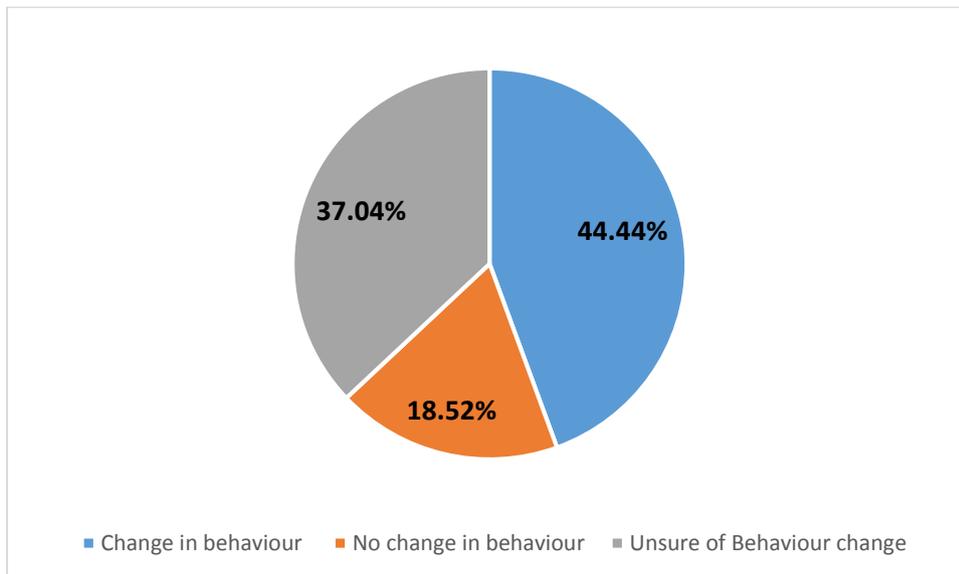


Figure 3.4.2: Reported changes in the child's behaviour during dental appointments.

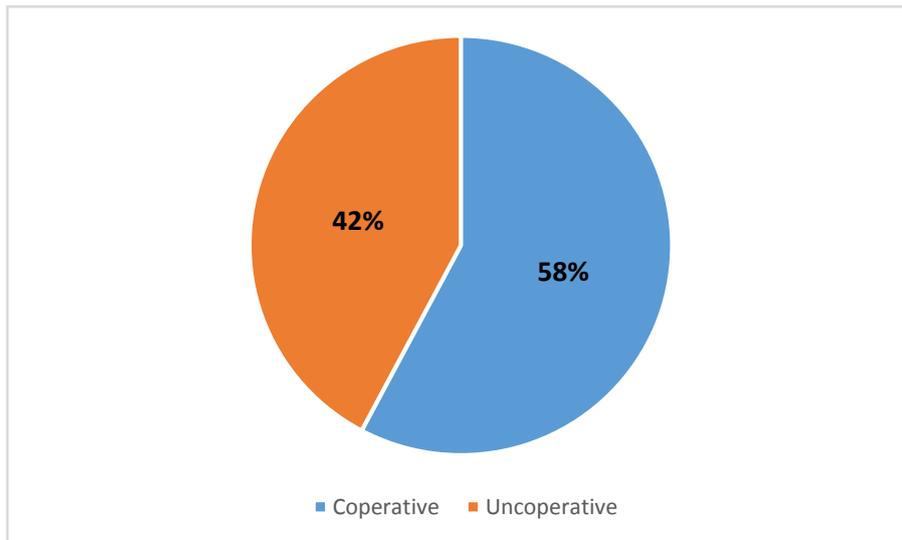


Figure 3.4.3: Reported cooperation of ASD children at the dentist.

Table 3.4.2: Behaviour shaping techniques attempted in the clinic as reported by the parents.

Behaviour Shaping measures attempted in the dental clinic	Yes	No	Total
Social story	20 (37%)	34 (63%)	54 (100%)
Modelling with peers	15 (27.8%)	39 (72.2%)	
Adhering to the same appointment time/ same dentist	27 (50%)	27 (50%)	

3.4.2. Patient experience

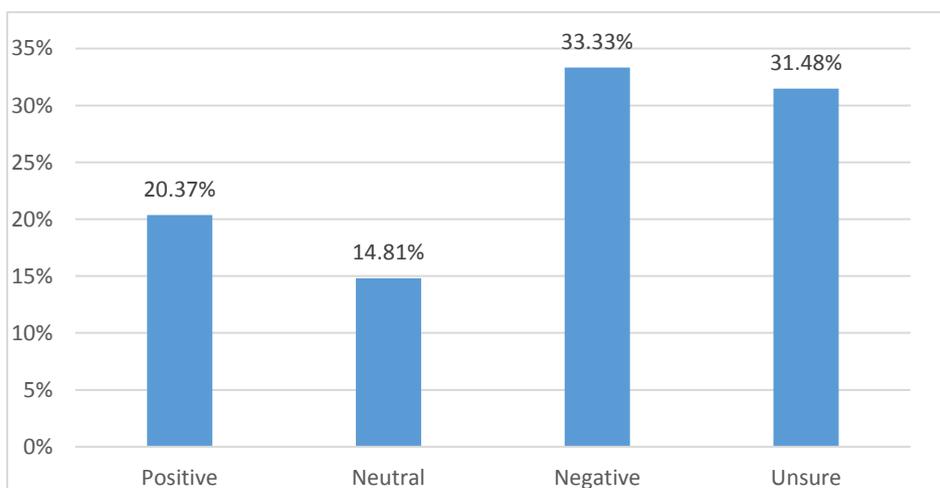


Figure 3.4.4: The child's experience during their last dental visit.

Table 3.4.3: Most common problems facing the child when visiting the dentist (as reported by the parents).

The problem(s)	Yes	No	Total
Lying down on the chair	14 (25.9%)	40 (74.1%)	54 (100%)
Chair lights	11 (20.4%)	43 (79.6%)	
Drilling sounds	22 (40.7%)	32 (59.3%)	
Putting something in their mouths	38 (70.4%)	16 (29.6%)	
Sharp instruments	17 (31.5%)	37 (68.5%)	

3.4.3. Treatment

3.4.3.1. Treatment Received

Only parents of children who have visited the dentist previously, answered the following question (n=43).

Table 3.4 4: Last dental procedure the child received in the clinic.

Dental procedure at child's last dental visit	n (%)
Regular check-up	20 (37%)
Filling(s)	5 (9.3%)
Extraction(s)	18 (33.3%)

3.4.3.2. Other treatment options

Table 3.4.5: The association between monthly household income and use of physical restraint to complete dental treatment.

Monthly household income	Has your child ever been physically restrained to complete dental treatment?		Total (N = 54)	p value
	Yes (n = 15)	No (n = 39)		
Above R10 000	3 (10.7%)	25 (89.3%)	28 (51.8%)	0. 002
R5 000 – R9 999	3 (27.3%)	8 (72.7%)	11 (20.4%)	
Below R5 000	9 (60%)	6 (40%)	15 (27.8%)	

Table 3.4.6: The association between the cooperation during dental treatment and physical restraint.

Level of the cooperation of the child	Has your child ever been physically restrained to complete dental treatment?		Total	p value
	Yes (n = 15)	No (n = 39)		
Cooperative	1 (10%)	9 (90%)	10 (18.5%)	0.035
Neutral	1 (20%)	4 (80%)	5 (9.3%)	
Uncooperative	12 (46.1%)	14 (53.9%)	26 (48.1%)	
Unsure	1 (7.7%)	12 (92.3%)	13 (24.1%)	

Table 3.4.7: The association between parental education and their preference towards pharmacotherapeutic management of their child.

Level of parental education	Do you prefer that your child's dental treatment is completed under General anaesthesia / sedation?		Total	p value
	Yes	No		
School education only	21 (91.3%)	2 (8.7%)	23 (42.6%)	0.013
Tertiary education and above	19 (61.3%)	12 (38.7%)	31 (57.4%)	

3.4.4. Regularity of dental visits

Parents of 45 (83.3%) ASD children have reported their children do not visit the dentist regularly. Of those, 43 parents reported the reasons for irregular attendance to the dental clinic (n=43).

Table 3.4.8: Reasons reported by the parents for irregular attendance to the dental clinic.

Reasons why the child does not visit the dentist regularly	n (%)
Child was uncooperative	19 (44.1%)
Specialist dentist needed	6 (14%)
Financial restraints	9 (20.9%)
Do not take child unless they were in severe pain	3 (7%)
No dental problems	6 (14%)

Table 3.4.9: The association between parental employment status and regular dental check-ups.

Employment status	Does your child visit the dentist regularly?		Total	p value
	No (n = 45)	Yes (n = 9)		
			(N = 54)	
Employed	26 (83.9%)	5 (16.1%)	31 (57.4%)	0.592
Unemployed	19 (82.6%)	4 (17.4%)	23 (42.6%)	

Table 3.4.10: The association between parental education and the regularity of dental visits.

Level of parental education	Does your child visit the dentist regularly?		Total	p value
	No (n = 45)	Yes (n = 9)		
			(N = 54)	
School education only	23 (100%)	0 (0%)	23 (42.6%)	0.004
Tertiary education and above	22 (71%)	9 (29%)	31 (57.4%)	

Table 3.4.11: The association between monthly household income and the regularity of dental visits.

Monthly household income	Does your child visit the dentist regularly?		Total (N = 54)	p value
	Yes (n = 9)	No (n = 45)		
Above R10 000	8 (28.6%)	20 (71.4%)	28 (51.9%)	0.049
R5 000 – R9 999	0 (0%)	11 (100%)	11 (20.4%)	
Below R5 000	1 (6.7%)	14 (93.3%)	15 (27.7%)	

3.4.5. Treatment facilities

Table 3.4.12: Facility at which the child most commonly receives treatment.

At which dental treatment facility do you usually seek treatment for your child?	N (%)
Community clinic	15 (27.8%)
Tertiary hospital	1 (1.8%)
Private clinic	38 (70.4%)

Table 3.4.13: The association between parental employment status and the facility where the child most commonly receives treatment.

Employment status	At which dental treatment facility do you usually receive treatment?			Total (N = 54)	p value
	Community Clinic (n = 15)	Private clinic (n = 38)	Tertiary hospital (n = 1)		
Employed	4 (12.9%)	26 (83.9%)	1 (3.2%)	31 (57.4%)	0.012
Unemployed	11 (47.8%)	12 (52.2%)	0 (0%)	23 (42.6%)	

3.4.6. Barriers to dental treatment

Table 3.4.14: Parental perceptions of barriers to dental treatment faced by their autistic children.

Variable	Never	Rarely	Sometimes	Often	Always	Total
Do you feel that you do not have enough time to take care of your child's oral health?	11 (20.4%)	8 (14.8%)	21 (38.9%)	6 (11.1%)	8 (14.8%)	54 (100%)
Do you feel that the cost of dental treatment is a barrier to taking your child to the dentist?	10 (18.5%)	4 (7.4%)	12 (22.2%)	6 (11.1%)	22 (40.7%)	
Have you ever experienced difficulties trying to find a dentist who was willing to treat your child?	15 (27.8%)	2 (3.7%)	11 (20.4%)	10 (18.5%)	16 (29.6%)	

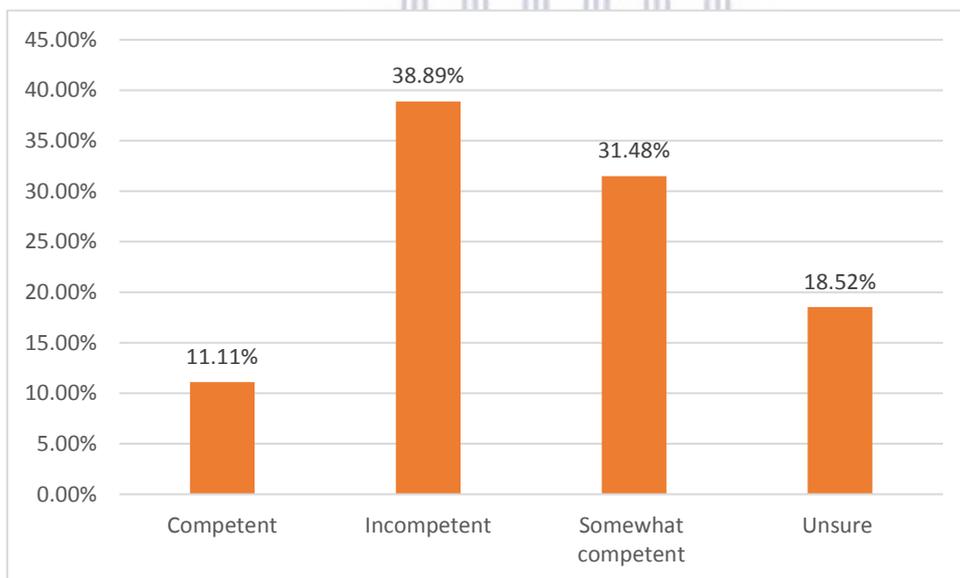


Figure 3.4.5: Parental perceptions regarding the competence of Oral Health Practitioners to manage children with ASD.

3.5. Parental description(s) of their autistic child’s behaviour in the dental office

Table 3.5.1: Qualitative analysis to responses of parents when describing the child’s behaviour at the dentist.

Themes	Codes	Quotes
Fear	<ul style="list-style-type: none"> • Panic • Anticipatory fear/worry 	“My son freaks out before we even reach the dentist”
Anxiety	<ul style="list-style-type: none"> • Discomfort • Scared 	“My child is scared uncomfortable and have anxiety regarding dentist”
Uncooperative behaviour	<ul style="list-style-type: none"> • Negative behaviour • Aggressive attitude • Avoidant behaviour 	<p>“Does not open his mouth and does not allow Dentist to view his mouth”</p> <p>“Extreme distress, crying, lashing out, kicking, hitting, bucking, trying to run away”</p>

3.6. Perceived support required from Oral Healthcare Professionals to manage children with ASD more effectively

Table 3.6.1: Parental perception of additional support required from Oral Health Professionals

Themes	Codes	Quotes
Practitioner competency	<ul style="list-style-type: none"> • Dentist’s knowledge/understanding of the child’s medical condition 	<p>“A real understanding of the sensory issues that ASD kids battle with’</p> <p>‘They don’t know how to handle a child with autism. No understanding for the diagnosis”</p> <p>“To understand and to be equipped to deal with children that are on the spectrum with Sensory Integration Issues experiencing oral challenges causing speech impediments”</p>

Table 3.6.1 (cont....)

Themes	Codes	Quotes
Dentist's soft skills	<ul style="list-style-type: none"> • Patience and empathy • Flexibility • Communication 	<p>"I believe if I could find a dentist that has enough patience to help my child even if it's at the cost of a small fee I'm more than willing to mentally prepare my child for a visit"</p> <p>"Flexibility is always appreciated as our sensory responses change and communication is very important. Even non-verbal people often can comprehend and appreciate being told what is happening"</p>
Financial factor	<ul style="list-style-type: none"> • Reduced costs to be able to visit the dentist • Homecare alternatives to improve oral health. • Prevention 	<p>"It should be a standard procedure to go in hospital with reduced rates"</p> <p>"Training in maintenance of the teeth and how to prevent and treat gum disease at home"</p> <p>"Better funded home support in general oral hygiene methods"</p>
Clinical environment	<ul style="list-style-type: none"> • Attractive dental clinic • Non-hostile approach • Fun • Short waiting time • Less anxiety 	<p>"A more welcoming environment. I recently saw a clinic that has a dinosaur bed and friendly pictures on the walls. A More playful approach is needed for all children in my opinion. They get in the chair, let's get it done - approach is detrimental to any child wanting to go back. A gentler and more fun approach is needed"</p> <p>"Not having to wait in the waiting room will help greatly in reducing anxiety build up"</p>
Parental perceptions	<ul style="list-style-type: none"> • Parent believes child cannot cooperate whatsoever • Treatment under GA preferred • Reduce trauma 	<p>'I think it's actually impossible to do any treatments to these kids in the chair'</p> <p>'Instead of making the process so long and traumatic they must give the parent ASAP a decision for doing the procedure under anaesthetic'</p>
Health promotion	<ul style="list-style-type: none"> • School shows • Media and television programs. 	<p>"Provide educational shows at schools"</p> <p>"Talk shows to encourage the kids"</p>

CHAPTER FOUR

DISCUSSION

4.1. Socio-demographics

A total of 54 parents participated in this study. Of these, the majority were biological parents with only three parents identifying themselves as adoptive parents (Table 3.1.1.). Roughly a third of the parents were younger than 40 years of age (Table 3.1.1.). One parent in the group was below 20 years and three parents were between the ages of 30 to 40 years. It has been documented in the literature that advancing maternal and paternal age are associated with an increased risk of having a child with autism (Reichenberg *et al.*, 2010). Increased parental age at birth is also linked to an earlier diagnosis of autism (Hrdlicka *et al.*, 2016). Paternal age at the time of childbirth was not recorded in our study. Therefore, the association between the parents' age and the increased chance of having a child with autism cannot be made.

The overwhelming majority of children in the present study were male (85.1%). This is in agreement with other literature, where males are more commonly diagnosed with autism than females (Head *et al.*, 2014). However, recent studies have shown that the female prevalence of autism has been underestimated (Teste *et al.*, 2021), mainly because females with Autism Spectrum Disorder (ASD) tend to have better developed social-skills and fewer repetitive behaviours than males. As a result, females are often underdiagnosed (Werling & Geschwind, 2013) and special attention is required during examination of females with suspected autism.

In the present study, seven of the children had another sibling with autism in the household. Siblings with autism have been studied in the literature, which supports the theory of genetics being a risk factor. Experts therefore consider genetic counselling to be an integral component in the diagnostic process (Lauritsen & Ewald, 2001).

4.1.1. Socioeconomic status and parental education

Regarding the socioeconomic status (SES) of the parents, close to 60% of parents were employed in full-time or part-time jobs, with roughly half of them earning a combined monthly income of more than R10 000 per month (Table 3.1.1). In the present sample, only five parents earned below R3 000 per month. Epidemiological studies have reported mixed findings regarding the association between family SES and ASD (Kelly *et al.*, 2019; King &

Bearman, 2011). Generally, when a high socioeconomic status was associated with increased prevalence of autism, this was often explained by having greater resources and improved access to experts able to diagnose autism (Thomas *et al.*, 2012). On the contrary, Hrdlicka *et al.* (2016) reported no significant association between parents' SES and the child's early diagnosis of autism. This study conducted in the Czech Republic supported findings from studies in the United States and Denmark- both being countries with open healthcare systems and established health insurance schemes. Due to differences in access to healthcare services, the association between SES and autism diagnosis is therefore not clear.

In relation to the education status, two parents had only primary school education, with 42.6% of parents having both primary and secondary school education. Close to 60% had tertiary education and above (Table 3.1.1.). It has been reported that a higher level of education is associated with an earlier age of diagnosis of autism (Hrdlicka *et al.*, 2016). Conversely, Kelly *et al.* (2019) reported that a substantial number of children who are born to mothers with a lower education level, are often undiagnosed.

An epidemiological study by Adak and Halder (2017) reported that parents with a high socioeconomic status and higher education levels tend to be more aware of their children's symptoms with more positive health-seeking behaviours, leading to an earlier diagnosis of ASD. This ties in closely with the fact that the bulk of the data relating to autism is generated in Western countries, while data from the African continent is very scarce (Adak & Halder, 2017). Children born to parents with fewer economic resources tend to be undiagnosed.

The majority of parents in our study were either married or cohabiting (74.1%), while the rest (25.9%) were single or divorced (Table 3.1.1.). Although some literature reports that ASD children are at a higher risk of living in a household not comprised of both parents due to a high divorce rate (Lofholm, 2008), this was not the case in the present study. The higher divorce rate has been explained by increased stress and depression among parents of children with ASD, often leading to termination of the marriage (Freedman *et al.*, 2012). Harteley *et al.* (2010) reported a 23.5% divorce rate amongst parents of children with autism, which is similar to the findings of the present study. Overall, there is not enough evidence to support the premise that having a child diagnosed with autism, solely leads to increased divorce rates among parents (Freedman *et al.*, 2012).

4.2. Medical History

In the current study, the interquartile range for autism diagnosis was three to five years (IQR = 3 - 5). It is well documented that early diagnosis is key for early interventions and improved quality of life for autistic children (Elder *et al.*, 2017). A study conducted in the Western Cape indicated that the majority of children diagnosed with autism were aged between five and seven years of age. The study postulated reasons for this delayed diagnosis, which were related to the South African context and healthcare system, with long waiting lists for possible diagnosis (Springer *et al.*, 2013). The high SES of parents in the present study may be linked to the relatively earlier age of diagnosis (i.e. 3 years old).

Of the 54 parents, 38.9% reported that their children had additional medical conditions besides autism (Table 3.2.1). Seven children (15%) were reported to have ADHD in addition to autism. This percentage is higher than findings documented by another study conducted in the Western Cape, which reported that 9.2% of children had ADHD in addition to autism (Louw, 2013). However, considering the sample size in Louw's (2013) study was 65 children, the numbers may be considered to be approximately similar. The other less frequently reported conditions included depression, asthma and epilepsy.

4.2.1. Pharmacologic treatment

There are several variable guidelines for the pharmacological treatment of children with autism (Armstrong, 2008). As reported by the parents, 61.1% of children in this study were not taking any medications for autism (Table 3.2.1.). Louw (2013) reported that 24.6% of children with ASD in the Western Cape used psychotropic medications. This percentage is lower than what has been reported elsewhere. Oswald and Sonenklar (2007) reported that up to 70% of children with autism were likely to be medicated before the age of eight years. This includes drugs such as antipsychotics, antidepressants and anxiolytics. The lower rate reported in this current study (and in that of Louw, 2013) may reflect poorer access to healthcare services in South Africa (Louw, 2013). This could possibly be in addition to financial restraints related to the high cost of medications.

In the current study, for those autistic children who were receiving medications, antipsychotics were the most commonly reported, at 75% (Figure 3.2.1.). The remaining 25% of medications used included Ritalin™, antidepressants and melatonin. This is consistent with the literature, as antipsychotics, antidepressants and stimulants were the most commonly

used psychotropics reported (Louw, 2013). Of clinical relevance is the fact that significant sleep problems are often associated with autism, for which melatonin is frequently prescribed (Malow *et al.*, 2016).

It has been reported that caries prevalence is significantly higher in children with ASD who are on prescribed medicines, particularly psychotropics (Kalyoncu & Tanboga, 2017). This may be due to xerostomia associated with the use of these medications. However, controversy exists in the literature, as other studies reported that, despite the side effects of the medications, it was not associated with increased caries risk (Klein & Nowak, 1999; Marshall *et al.*, 2010). In addition to this, parents may sometimes administer medications with sweet drinks to enhance the child's acceptance and intake thereof (Kalyoncu & Tanboga, 2017), possibly resulting in a higher caries prevalence. Previously, syrup medications included sweeteners to enhance child compliance. These are however no longer used (Baribeau & Anagnostou, 2014).

4.2.2. Behavioural therapy

Behavioural Therapy (BT) is an effective treatment for anxiety disorders in autistic children (Maughan & Weiss, 2017). In the current study, 40.7% of parents stated that their child(ren) had previously undergone some form of BT (Table 3.2.1). The median number of years for time spent in behaviour therapy was 1.5 years (IQR: 0.75 to 2.5).

4.2.3. Self-injurious behaviour

When the incidence of self-injurious behaviour (SIB) was explored (Table 3.2.1), approximately 80% of parents stated that their child(ren) exhibited no signs of SIB. The minority (20.3%) reported that their child(ren) demonstrated at least one type of SIB. From the qualitative data analysis, it was noted that five parents reported incidents of head-banging, while four parents reported that their children were scratching themselves. These findings are echoed by Canitano (2006), where head-banging and lip-biting were most commonly reported. Young age (below five years) and severe mental retardation are general risk factors for SIB (Canitano, 2006). This may explain the low percentage of SIB reported in this study, as the majority of the children were aged eight years and above (57.4%). Other less common self-injurious behaviours reported in the current study included children hitting their own bodies (3), biting themselves (2) and hair pulling (1).

In the literature, SIB has been linked to an increased incidence of soft tissue trauma (Gandhi & Klein, 2014). SIB may also occur due to inability to communicate, which includes communicating oral pain. Emotional outbursts and temper tantrums with SIB in the dental clinic could be induced by the exposure to an unfamiliar setting (Gandhi & Klein, 2014). Management of SIB requires the cooperative involvement of a psychologist, psychiatrist, and occupational therapist along with dental professionals (Gandhi & Klein, 2014).

4.3. Challenges to oral health care practices at home

In the present study, roughly 20% of the children refused to brush their teeth most of the time (Table 3.3.1). Only 20.4% of the children brushed alone without assistance, while 58% required some form of parental involvement to achieve adequate oral hygiene.

4.3.1. Brushing habits

Parental assistance includes actively helping the child with tooth brushing, whereas supervision involves the parent being physically present during brushing to ensure thorough cleaning (Huebner & Riedy, 2010). Alshihri *et al.* (2020) reported similar findings to the present study (Table 3.3.1), where only 16.9% of children in their sample did not brush their teeth at all and 21.2% brushed alone without assistance. Similarly, a study in Brazil reported that 31% of autistic children did not brush their teeth daily and 64.2% received help from an adult (Hage *et al.*, 2020).

Due to undeveloped hand-eye coordination, it is recommended that parents must actively brush for children below the age of six years and assist them until the age of seven (Ceyhan *et al.*, 2018). However, autistic children often require assistance with brushing their teeth for a protracted period of time, due to poor hand coordination and lack of good motor control (Vajawat & Deepika, 2012). Moreover, autistic children also dislike brushing due to hypersensitivity to sensory stimulation (sound, touch and light) (AlHumaid *et al.*, 2020). Teste *et al.* (2021) reported high family involvement (87.8%) during once daily oral hygiene practices of autistic children. A quarter of the parents in their study reported experiencing stress during tooth brushing. A higher percentage was reported in the present study, with above 90% of parents who assisted and/ or supervised their children during brushing, stating that it was not easy to perform (Table 3.3.1). In a qualitative study by Lewis *et al.* (2015), parents reflected on their own experiences and some reported that keeping a specific routine of brushing (time of brushing and method) helped the child cope better with the process.

AlHumaid *et al.* (2020) reported that 29.3% of ASD children in their sample brushed their teeth without assistance- a fraction higher than what was reflected in our results (Table 3.3.1). However, their sample included older children and teenagers from six to eighteen years of age. Nevertheless, this suggests that parental involvement with oral hygiene practices should continue into adulthood, a finding, which was supported by Orellana *et al.* (2012) in a sample of adults with autism who still required assistance with brushing (25%).

No association was found between brushing habits and the child's sex (Table 3.3.2) or age, parental marital status, employment status, monthly household income or whether the child had undergone Behaviour Therapy or not.

Using the Fisher's exact test, a statistically significant association of 0.043 was found between parental education and the child's brushing habits, at a 0.05 alpha level (Table 3.3.3). Generally, it has been reported that higher parental education levels are associated with better oral health knowledge and better oral hygiene practices in their children (Chen *et al.*, 2020). Higher maternal education was also associated with a significantly positive impact on oral health-related quality of life of their autistic children (Pani *et al.*, 2013).

Regarding the tools used for brushing, 87% brushed with toothpaste and a toothbrush, while 13% only used a cloth for cleaning (Table 3.3.1). In this study, 46.3 % of parents reported they previously tried using an electric toothbrush and 48% of those found it easier to use, as the child was more cooperative (Table 3.3.1). An electric toothbrush has been shown to be a viable option to enhance acceptance of brushing in children with ASD (Delli *et al.*, 2013). The Chi squared test revealed a statistically significant association between parental education and whether they have tried using an electric toothbrush previously to clean their autistic child's teeth ($p = 0.044$) (Table 3.3.6.). This may be explained by the more positive attitudes of highly educated parents in addition to increased awareness and continuous intentions to improve their children's oral health.

Parents reported that 42.6% of the children swallowed the toothpaste during brushing. Similarly, this was reported in a study by Du *et al.* (2019), where parents complained that ASD children tended to swallow toothpaste excessively. Therefore, to avoid the risk of fluorosis, it is recommended to use a smear of children's toothpaste during brushing for children below three years of age and a pea-sized amount for children aged three-to-six years (AAPD, 2018).

Vajawat and Deepika (2012) studied the brushing frequency of autistic children and reported results similar to the current study, where 66% brush only once daily. However, there was no statistically significant difference when compared to non-autistic children. In the present study, no statistically significant association was found between the child's daily brushing frequency and their age, sex or the parental education level or employment status.

4.3.2. Oral hygiene aids

All of the parents in the present study have never used a device to keep their child's mouths open during brushing. Ninety percent of parents reported that their children do not practice flossing (Table 3.3.1). Because only five children in this sample were reported to floss their teeth, the questions in the questionnaire regarding the use of floss holders were not included in the results.

A third (33.3%) of the parents reported that they had tried another method of plaque control, which consisted mainly mouthwashes. This finding was consistent with another study where the occasional use of a mouthwash (in the absence of flossing) was noted in autistic patients under supervision of caretakers (Vajawat & Deepika, 2012). However, the study compared autistic and non-autistic children and no significant difference was reported in relation to the absence of flossing (Vajawat & Deepika, 2012). Magoo *et al.* (2015) reported that 30% of parents in their sample tried additional oral hygiene aids with their autistic children. However, they considered this percentage to be low.

A statistically significant association was found between the child's age and whether the parents had tried other plaque control methods (Table 3.3.4) such as the use of mouthwash ($p = 0.004$). This is in accordance with the AAPD's recommendation that mouthwashes should only be prescribed for children with a developed swallowing reflex, from the age of six years and older (AAPD, 2018). In the case of children with ASD, the parent must ensure that the child can spit and not swallow the mouthwash to avoid ingestion of unnecessary fluoride or chlorohexidine (depending on the mouthwash indicated for use).

In addition, the Chi squared test revealed a statistically significant association between the parents' marital status and whether the parents have tried other plaque control methods ($p = 0.028$) (Table 3.3.5). Households comprised of both parents are more likely to spend time and money on preventative dental care.

4.3.3. Oral habits

Oral habits were reported by 44.4% (Table 3.3.1) of parents within this sample of autistic children. Of these, the most commonly reported habit was nail biting (24.7%), followed by mouth-breathing (16.6%), lip-biting (7.4%) and thumb-sucking (7.4%) (Figure 3.3.1.). Contrary to the prevalence of habits reported on in this study, Al-Sehaibany (2017) reported bruxism to be the most common habit among autistic children. Similarly, Nagendra and Jayachandra (2012) also noted bruxism to be the most common habit presenting in children with autism.

Half the parents in this current study who reported that their children have oral habits, stated that they had tried to help the child to stop the habit. Qualitative analysis was employed to investigate methods used by parents to stop oral habits. Two main themes emerged, with three parents using nail polish to discourage nail biting and another three parents trying intensive nail grooming regimes. One parent wrote: *"I try to keep his nails as short as possible all the time"*. Despite this, two parents wrote: *"the child still finds ways to bite them"*. To stop other oral habits from developing, two parents said that they had tried verbal reminders and one parent reported that they consulted with the dentist in this regard.

4.4. Challenges to oral health care in the clinic

4.4.1. Behaviour and cooperation

The majority (48.1%) of parents described their child's usual (or general) response at the dentist as being negative (Figure 3.4.1), and 44.4% reported that their child's behaviour changed negatively as soon as they visited the dentist (Figure 3.4.2). Similarly, Marshall *et al.* (2008) was not able to successfully examine 30% of their sample of ASD children (20) due to poor cooperation. Behaviour was predicted to be uncooperative, particularly for non-verbal ASD children and those who were 6 years and above and unable to read (Marshall *et al.*, 2007).

Adhering to the same appointment and same dentist was the most attempted method for Behaviour Shaping in the clinical setting (50%) (Table 3.4.2). Barry *et al.* (2014) reported that parents found it particularly helpful when dental appointments were of short duration and arranged in the mornings. Overall, the dental clinic represents an anxiety-provoking environment. Therefore, adhering to the same dentist and establishing a rapport with the dentist results in decreased stress.

4.4.2. Patient experience

When asked about their child's last dental visit, 33.3% of parents described it as being negative (Figure 3.4.4). However, some parents were unsure how to describe their child's behaviour (31.5%). The most common reason for discomfort in the clinical environment, as reported by the parents, was when something was put into the child's mouth (70.4%) (Table 3.4.3.). This can be explained by the principle of oral defensiveness, as children with ASD often present with hypersensitivity intraorally and peri-orally (Delli *et al.*, 2013).

4.4.3. Treatment

4.4.3.1. Treatment received

Approximately one third of the children received extractions in their last dental visit (Table 3.4.4). This is consistent to what was reported by Mansoor *et al.* (2018), where extraction was the most commonly performed procedure amongst autistic children. Hage *et al.* (2020) reported that 35% of families with autistic children do not attend regular preventative visits, but children mainly receive extractions as the main treatment option. Önel and Kirzioğlu (2018) compared autistic and non-autistic children and found that a significantly higher number of permanent teeth were extracted in autistic children. This could be explained by two reasons: the lack of cooperation necessary to facilitate the provision of adequate restorative treatment (other than extraction), and/ or delayed presentation of patients for dental treatment where teeth are then deemed unrestorable when they do visit the dentist.

4.4.3.2. Other treatment options

Close to 30% of children in this study have reportedly been physically restrained at least once in order to complete dental treatment (Table 3.4.1). This is despite the recent literature recommending against physical restraint as it is considered to be controversial, particularly in children with special medical needs (Chandrashekhar & Bommangoudar, 2018).

A statistically significant association was found between monthly household income and the use of physical restraint in order to complete dental treatment ($p = 0.002$) (Table 3.4.5). This is an inverse relationship where parents with higher monthly household incomes were more likely to refuse physical restraint of their children. Similar findings were reported by Oliveira *et al.* (2007), where a statistically significant relationship between active physical restraint amongst children with intellectual disability and their parents' economic status was identified. In their study, participants from a less privileged economic background had a 1.9

times greater chance of receiving active physical restraint than those from the more privileged economic classes. This can be explained by the following: parents with a lower socioeconomic status often face difficulties with access to dental care. It is likely that they believe if they do not accept the physical restraint, their child would not be treated. On the other hand, parents with higher incomes have better access to other treatment options such as sedation or general anaesthesia (GA).

In the present study, a statistically significant association was found between the cooperation of the child with dental treatment and use of physical restraint in order to complete treatment ($p= 0.035$) (Table 3.4.6). This can simply be explained by the absence of the need to use physical restraint in children that are more cooperative (and vice versa). However, no association was found between cooperation and previous GA and/ or sedation experiences.

Approximately 35% of children in the present study received previous dental treatment under sedation or GA (Table 3.4.1). In addition, pharmacotherapeutic treatment was preferred by 74.1% of parents for the treatment of their children. Recent literature has shown a growing acceptance of pharmacological techniques by parents (Sanjeevi *et al.*, 2019). This is in line with research exploring parental preferences among parents of children with ASD, where 59% of parents stated that they would prefer their children to have dental treatment under GA (Capozza & Bimstein, 2012).

In this study, a statistically significant association was found between parental education status and their preference towards treating their children under sedation or GA ($p= 0.013$) (Table 3.4.7). Educated parents are more able to comprehend the benefits of treatment under sedation or GA. No significant association was found between parental employment status or marital status and their preference towards treatment under sedation or GA. No significant association was also found between previous GA or sedation experiences and the child's age, or sex or the parent's employment status or education level.

4.4.4. Regularity of dental visits

In excess of 83% of parents in this sample reported that their autistic child does not visit the dentist regularly (Table 3.4.1). For ASD children, regular visits to the dentist should occur every three to six months due to their medical condition(s) and associated oral health challenges (AAPD, 2020). However, it has been reported that 50% of ASD children have never visited the dentist (Magoo *et al.*, 2015). This is aligned with the findings of the present study.

Parents were asked the reason why their child does not visit the dentist regularly and many chose more than one option (Table 3.4.8), with roughly 42% stating that it was because the child could not cooperate with dental treatment. Nine parents (16.7%) reported they could not afford to visit the dentist. Other reasons included that the parents thought that a specialist dentist was needed to treat their children (6); that their child's teeth are in good condition (6); or they do not take the child to the dentist unless they are in severe dental pain (3). This concurs with Barry *et al.* (2014), who reported that the child's negative behaviour was the most common reason for failing to access dental care for children with ASD. Additionally, the negative attitudes of parents were mainly related to finding a dentist who understood their child's condition (AlHumaid *et al.*, 2020). Magoo *et al.* (2015) reported similar barriers, which mainly included a lack of cooperation of the child and the unaffordable costs of dental treatment.

In this study, no association was found between parental employment status and regularity of visits to the dentist (Table 3.4.9). However, a statistically significant association was found between parental education and the regularity of dental visits ($p = 0.004$) at a 0.05 alpha level (Table 3.4.10). Moreover, a statistically significant association was found between monthly household income and the regularity of the child's dental visits ($p = 0.049$) (Table 3.4.11). These findings are supported by the literature, as in a systematic review by Badri *et al.* (2014), where a significant correlation between children's adherence to regular dental attendance and parents' level of education and their economic status was reported on in nine different studies. This is in line with a simple concept, which is that oral health is socially determined in terms of income, education and employment. Low income and low education results in poorer oral health seeking behaviour of parents and their children, and vice versa.

In the present study, no association was found between regular check-up appointments at the dentist and any of the following variables: the child's age, the child's sex, previous Behaviour Therapy and the marital status of the parents.

4.4.5. Treatment facilities

The majority of parents in this cohort (70.4%) reported that their child received treatment at a private clinic (Table 3.4.12.). Using the Chi squared test, a statistically significant association ($p = 0.012$) was found between parental employment status and the facility at which the child most commonly received dental treatment (Table 3.4.13.). This translates to children of

employed parents being more likely to receive treatment at a private dental facility. This is directly related to income stability of employed parents or possibly having health insurance that is linked to their employment.

No association was found between the treatment facility where the child most commonly received treatment and the child's sex, cooperation at the dentist (as reported by the parent) or the child having to be physically restrained or not. Similarly, no association was also found between where the child receives treatment and if they had any previous GA and/ or sedation experiences.

4.4.6. Barriers to dental treatment

The child's autism seems to be the main barrier to professional dental treatment according to Alshihri *et al.* (2021). Similarly, in the current study, 61.1% of parents believed that their children's attitude discourages them from taking their autistic child to the dentist. Focussing on the dentist, 38% of the parents were of the opinion that oral healthcare practitioners are not adequately trained to manage autistic children (Figure 3.4.5).

Children with ASD are highly dependent on their parents, even for their basic needs. In the open-ended questionnaire, 18% of parents stated that they always felt as if they did not have enough time to take care of their child's oral health. Moreover, this section of the study clearly demonstrated the struggles and frustrations parents go through in the dental clinic with their children. One parent elaborated: *"So far I have not found a dentist that can help. My child had a very bad first dentist appointment and I honestly want to change how he see such a needy service. He needs the attention of a dentist and I am open to the possibility of referrals"*. Another parent expressed their stress and struggle: *"We as parents are already aware of the challenges our kids present with, we don't need the added pressure from dentists and their assistants telling us to hold our child down, while others are waiting for their turn"*.

4.5. Parental description(s) of their autistic child's behaviour in the dental office

Qualitative responses to questions posed to the parents are reported on below.

The question posed was: "How does your child's behaviour change when you visit the dentist?"

The information was largely interconnected. However, three main themes emerged, namely fear, anxiety and lack of cooperation (Table 3.5.1.). Qualitative studies describing the

response of ASD children at the dentist are lacking. However, parents of autistic children in a study by Stein *et al.* (2012) mainly reported lack of cooperation of the children by refusing to open their mouths or continuous screaming due to sensory sensitivities (e.g. bright lights or loud sounds).

4.6. Perceived support required from Oral Healthcare Professionals to manage children with ASD more effectively

The question posed was: “What additional support do you feel you need from Oral Health Professionals in order to provide adequate dental treatment for your child?”

In this section, the parents elaborated on their children’s previous experiences and the support they think they need to improve the oral health care of their children (Table 3.6.1.). The first and second themes which emerged were related to the practitioners themselves, their competence and soft skills. The third and fourth theme were the affordability of the healthcare services and an appealing clinical environment respectively. The fifth theme that emerged from coding the data set, identified factors that are associated with parental perceptions. Lastly, the sixth theme speaks to the provision of health promotion support within the community through schools and media.

When comparing this to other literature, some emergent themes were similar. The clinical environment and particularly the waiting room, posed an anxiety provoking area (Lewis *et al.*, 2015). According to other parents of ASD children, this was to the point where they preferred waiting in the car until they were called to the examination room (Lewis *et al.*, 2015). Another important point was preparation before the dental visit using social stories followed by very slow introduction to the dental environment and excellent communication by the dentist. A significant factor was also the cost of dental care, which is directly related to unmet dental needs (Lai *et al.*, 2011). This was coupled with the absence of health insurance to cover the child’s treatment expenses.

Parental perceptions also need to be taken into consideration. Parents demanded to be heard, as they believe they know their children and what works for them better (Lewis *et al.*, 2015). Several parents also argued that some behaviour shaping techniques which were used for their other ‘typically developing children’, do not work in autistic children (Lewis *et al.*, 2015). Dentists must therefore listen carefully to the parents and preferably establish a pre-visit communication with them even if it is over the phone. In relation to practitioners

themselves, parents with ASD are more likely to report difficulties with access to dentists who are willing and capable of providing care for their children (Barry *et al.*, 2014). This could be due to lack of training provided or lack of available resources. Nevertheless, referral and guidance should be provided to the parents.



CHAPTER FIVE

LIMITATIONS OF THE STUDY

Several limitations in this study are duly acknowledged. The main limitation is the small sample size of the study. Due to the restrictions imposed by the Covid-19 pandemic, data had to be collected via online questionnaires, which changed the original methodology. It was therefore challenging to reach participants to meet the original estimated sample size. Moreover, face-to-face interview questionnaires could have generated data that would have been more detailed and context specific and would have allowed the researcher to probe certain areas of concern that the parents had. However, due to the Covid pandemic, this option was not feasible, as face-to-face contact was not permitted during this time and hence the original methodology was amended in accordance with appropriate protocols at that time. In an attempt to compensate for this limitation, open-ended questions were incorporated into the online questionnaire, in a bid to generate as much information-rich data from the sample population as possible.

Another possible limitation of this study could be a selection bias. Perhaps, those who do not have access to autism support groups have greater needs and experience more barriers to oral health care. Finally, being able to investigate the clinical assessment of the dentist towards the child's behaviour could have provided more reliable information compared to the caregiver's assessment alone.

CHAPTER SIX

CONCLUSIONS AND FUTURE RECOMMENDATIONS

6.1. Conclusions

In the current study, ASD children were diagnosed with autism at a mean age of 3 years old. The majority were not medicated which is perhaps linked to deficiencies within the South African healthcare system related to access to healthcare and affordability of autism medications. Self-injurious behaviour was not prevalent; however, head-banging was the most commonly reported.

Findings of this study suggest that children with ASD require long-term assistance with daily oral hygiene practices. Parents must actively assist or supervise brushing, flossing and other oral hygiene methods. This task is often not easy to achieve, which can put great strain upon members of the household. Whether it was due to the absence of knowledge or due to difficulty of implementation, the absence of flossing (particularly in this sample of children) was striking and needs to be addressed. Oral habits were reported in almost half of the children and almost all parents did not consult with a dentist previously to try and stop the habit.

In the dental clinic, the uncooperative behaviour of children with ASD tends to dominate the clinical session, making it the main barrier to dental treatment according to parents. The clinical environment represents an anxiety-provoking space with approximately 70% of children displaying uncooperative behaviour when something is placed in their mouths, due to ASD-associated oral defensiveness. Parents, therefore, desperate to receive dental care for their children, become more accepting of alternatives, such as physical restraint or treatment under sedation or GA. In relation to the dental treatment performed, preventative visits were minimal and extraction was the most common procedure performed in the dental office.

This study could provide dentists with an in-depth understanding of the challenges that children with ASD and their parents face when carrying out daily oral hygiene measures. This would be in addition to using suitable behaviour shaping techniques in the dental clinic to better facilitate dental treatment. Our findings emphasise that dentists need to approach autistic children in the clinic with empathy. Empathy should be supported by appropriate

knowledge and skills to be able to manage children with this condition more effectively. Autism has a very broad scope of clinical presentation and future dental research should focus on safe, case-specific experimentation with child-management techniques, which could be particularly useful for the various categories of autism. Moreover, this research highlights the effects of different socio-demographic factors on parental choices in relation to oral health care for their children. It would be worthwhile to investigate those challenges in families with low socioeconomic status, so as to provide them with specific recommendations according to their available resources.

6.2. Recommendations

6.2.1. Recommendations to parents

Recommendations to the parents should emphasise the importance of early dental visits and regular follow-up appointments. Irregular visits to the dentist leads to the deterioration of the oral health status of the children and often leaves the dentist with limited treatment options (e.g. extraction only). Therefore, parents need to receive timely and accurate advice on the importance of prevention and should be introduced to all at-home oral health care alternatives, which could facilitate oral health promotion. Flossing, in particular, should be introduced with the use of adjuncts such as floss holders or flossettes to make the process easier.

6.2.2. Recommendations to oral health professionals

Dentists have a huge responsibility to prepare themselves before the dental visit with an autistic child. Sufficient knowledge regarding autism, coupled with good communication skills and patience, are keys to a successful visit. Likewise, pre-visit communication with the parents and understanding the severity of autism of the child patient are also important. Alternative oral hygiene methods (such as the use of an electric toothbrush) should be suggested and encouraged when possible.

In the dental clinic, waiting times before the visit should be minimized and ensuring the same dentist treats the patient every time is ideal, preferably during an early morning appointment. Abrupt or loud voices and distracting lights should be minimized and dentists should consider opting for treatment under sedation or GA if needed. General dentists who feel incompetent

treating and managing an ASD child should rather refer the child to a specialised Paediatric Dentist or a practitioner with adequate skills in this regard

6.2.3. Recommendations to institutions (special needs schools/ Autism support groups)

Schools can be of great assistance to parents and dentists. ASD children respond positively to social stories, which can be introduced at a school level. In addition, brushing can be practiced routinely in school with the introduction of a practical oral health programme.

Autism foundations and support groups should help raise the awareness of parents regarding the importance of oral health care for ASD children, with the promotion of optimal oral health through different media platforms. Governmental bodies should assist with financial issues which often hinder access to oral health care within the community. The provision of health insurance for autistic children, including covering all the basic oral health care needs, will encourage parents to attend regular dental visits, which would reduce the burden of disease in this very susceptible group of children.



REFERENCES

Adak, B. & Halder, S. (2017). Systematic review on prevalence for autism spectrum disorder with respect to gender and socio-economic status. *Journal of Mental Disorders and Treatment*, 3(1), 1-9.

AlHumaid, J., Gaffar, B., AlYousef, Y., Faris, A., Alhareky, M. & El Tantawi, M. (2020). Oral Health of Children with Autism: The Influence of Parental Attitudes and Willingness in Providing Care. *The Scientific World Journal*, 2020, 8329426.

Al-Sehaibany, F.S. (2017). Occurrence of oral habits among preschool children with Autism Spectrum Disorder. *Pakistan Journal of Medical Sciences*, 33(5), 1156.

Alshihri, A.A., Al-Askar, M.H. & Aldossary, M.S. (2020). Brief report: At-home oral care experiences and challenges among children with Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, 79, 101679.

Alshihri, A.A., Al-Askar, M.H. & Aldossary, M.S. (2021). Barriers to Professional Dental Care among Children with Autism Spectrum Disorder. *Journal of autism and developmental disorders*, 51(8), 2988-2994.

American Academy of Pediatric Dentistry. (2018). Fluoride therapy. *The Reference Manual of Pediatric Dentistry*. Chicago, IL: American Academy of Pediatric Dentistry, 302-5.

American Academy of Pediatric Dentistry. (2020). Caries-risk assessment and management for infants, children, and adolescents. *The Reference Manual of Pediatric Dentistry*. Chicago, IL: American Academy of Pediatric Dentistry, 243-7.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*. 5th ed. Washington, DC: APA.

Ametepeee, L. K, & Chitiyo, M. (2009). What We Know about Autism in Africa: A Brief Research Synthesis. *Journal of the International Association of Special Education*, 10(1).

Armstrong, C. (2008). AAP releases guidelines on management of autism spectrum disorders. *American Family Physician*, 78(12), 1399.

Bäckman, B. & Pilebro, C. (1999). Visual pedagogy in dentistry for children with autism. *ASDC journal of dentistry for children*, 66(5), 325-31.

Badri, P., Saltaji, H., Flores-Mir, C. & Amin, M. (2014). Factors affecting children's adherence to regular dental attendance: a systematic review. *The Journal of the American Dental Association*, 145(8), 817-828.

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z. ...& Dowling, N. F. (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *Central of disease control and infection (CDC)*, 67(No. SS-6), 1-23. Available from: <https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm> (Last accessed: 25 April 2022).

Bakare, M.O. Munir, K. (2011). Autism spectrum disorders (ASD) in Africa: A perspective. *African Journal of Psychiatry*, 14(3):208-10. Available from: <http://dx.doi.org/10.4314/ajpsy.v14i3.3> (Last accessed: 5 March 2022).

Barbaresi, W. J., Katusic, S. K. & Voigt, R. G. (2006). Autism: A review of the state of the science for pediatric primary health care clinicians. *Archives of Pediatrics and Adolescent Medicine*, 160(11), 1167-1175.

Baribeau, D. A. & Anagnostou, E. (2014). An update on medication management of behavioral disorders in autism. *Current psychiatry reports*, 16(3), 1-13.

Barry, S., O'Sullivan, E.A. & Toumba, K.J. (2014). Barriers to dental care for children with autism spectrum disorder. *European Archives of Paediatric Dentistry*, 15(2), 127-134.

Bartolomé-Villar, B., Mourelle-Martínez, M. R., Diéguez-Pérez, M. & de Nova-García, M. J. (2016). Incidence of oral health in paediatric patients with disabilities: Sensory disorders and autism spectrum disorder. Systematic review II. *Journal of Clinical and Experimental Dentistry*, 8(3), e344.

Baykal, S., Karakurt, M. N., Çakır, M. & Karabekiroğlu, K. (2019). An Examination of the Relations Between Symptom Distributions in Children Diagnosed with Autism and Caregiver Burden, Anxiety and Depression Levels. *Community Mental Health Journal*, 55(2), 311-317.

Braun, V. & Clarke, V. (2012). Thematic analysis. *APA handbook of research methods in psychology*, Vol. 2: Research designs: Quantitative, qualitative, neuropsychological, and biological (pp. 57-71). Washington, DC: American Psychological Association.

Brereton, A. V., Tonge, B. J. & Einfeld, S. L. (2006). Psychopathology in children and adolescents with autism compared to young people with intellectual disability. *Journal of Autism and Developmental disorders*, 36(7), 863-870.

Bromley, J., Hare, D. J., Davison, K. & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, 8(4), 409-423.

Canitano, R. (2006). Self injurious behavior in autism: clinical aspects and treatment with risperidone. *Journal of neural transmission*, 113(3), 425-431.

Capozza, L.E. & Bimstein, E. (2012). Preferences of parents of children with autism spectrum disorders concerning oral health and dental treatment. *Pediatric Dentistry*, 34(7), 480-484.

Ceyhan, D., Akdik, C. & Kirzioglu, Z. (2018). An educational programme designed for the evaluation of effectiveness of two tooth brushing techniques in preschool children. *European Journal of Paediatric Dentistry*, 19(3), 181-186.

Chandrashekhar, S. & Bommangoudar, J.S. (2018). Management of autistic patients in dental office: a clinical update. *International Journal of Clinical Pediatric Dentistry*, 11(3), 219.

Charles, J.M. (2010). Dental care in children with developmental disabilities: attention deficit disorder, intellectual disabilities, and autism. *Journal of Dentistry for Children*, 77(2), 84-91.

Chen, L., Hong, J., Xiong, D., Zhang, L., Li, Y., Huang, S. & Hua, F. (2020). Are parents' education levels associated with either their oral health knowledge or their children's oral health behaviors? A survey of 8446 families in Wuhan. *BMC Oral Health*, 20(1), 1-12.

Como, D. H., Stein Duker, L. I., Polido, J. C., & Cermak, S. A. (2021). Oral health and Autism Spectrum Disorders: A unique collaboration between dentistry and occupational therapy. *International journal of environmental research and public health*, 18(1), 135.

Currenti, S.A. (2010). Understanding and Determining the Etiology of Autism. *Cellular and Molecular Neurobiology*, 30(2), 161-171. Available from: <https://doi.org/10.1007/s10571-009-9453-8> (Last accessed: 30 January 2022).

Da Silva, S. N., Gimenez, T., Souza, R. C., Mello-Moura, A. C. V., Raggio, D. P., Morimoto, S., Lara, J. S., Soares, G. C. & Tedesco, T. K. (2017). Oral health status of children and young adults

with autism spectrum disorders: systematic review and meta-analysis. *International Journal of Paediatric Dentistry*, 27(5), 388-398.

DeFilippis, M. (2018). Depression in children and adolescents with autism spectrum disorder. *Children*, 5(9), 112.

Delli, K., Reichart, P.A., Bornstein, M.M. & Livas, C. (2013). Management of children with autism spectrum disorder in the dental setting: concerns, behavioural approaches and recommendations. *Medicina oral, patologia oral y cirugia bucal*, 18(6), e862.

DeMattei, R., Cuvo, A. & Maurizio, S. (2007). Oral assessment of children with an autism spectrum disorder. *American Dental Hygienists' Association*, 81(3), 65-65.

Du, R. Y., Yiu, C. C., Wong, V. C. & McGrath, C. P. (2015a). Autism developmental profiles and cooperation with oral health screening. *Journal of Autism and Developmental disorders*, 45(9), 2758-2763.

Du, R. Y., Yiu, C. K., King, N. M., Wong, V. C. & McGrath, C. P. (2015b). Oral health among preschool children with autism spectrum disorders: A case-control study. *Autism*, 19(6), 746-751.

Du, R.Y., Yiu, C.K. & King, N.M. (2019). Oral health behaviours of preschool children with autism spectrum disorders and their barriers to dental care. *Journal of Autism and Developmental Disorders*, 49(2), 453-459.

Elder, J. H., Kreider, C. M., Brasher, S. N. & Ansell, M. (2017). Clinical impact of early diagnosis of autism on the prognosis and parent-child relationships. *Psychology Research and Behavior Management*, 2017(10), 283-292.

Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C., Montiel-Nava, C., Patel, V., Paula, C. S., Wang, C., Yasamy, M. T. & Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research*, 5(3), 160-179.

Fakroon, S., Arheiam, A. & Omar, S. (2015). Dental caries experience and periodontal treatment needs of children with autistic spectrum disorder. *European Archives of Paediatric Dentistry*, 16(2), 205-209.

- Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research*, 65(6), 591.
- Francis, K. (2005). Autism interventions: a critical update. *Developmental Medicine and Child Neurology*, 47(7), 493-499.
- Freedman, B. H., Kalb, L. G., Zablotsky, B. & Stuart, E. A. (2012). Relationship status among parents of children with autism spectrum disorders: A population-based study. *Journal of Autism and Developmental Disorders*, 42(4), 539-548.
- Gandhi, R. P., & Klein, U. (2014). Autism spectrum disorders: an update on oral health management. *Journal of Evidence Based Dental Practice*, 14, 115-126.
- Gardener, H., Spiegelman, D. & Buka, S. L. (2009). Prenatal risk factors for autism: comprehensive meta-analysis. *The British Journal of Psychiatry*, 195(1), 7-14.
- Geschwind, D. H. & State, M. W. (2015). Gene hunting in autism spectrum disorder: on the path to precision medicine. *The Lancet Neurology*, 14(11), 1109-1120.
- Gray, C. (2010). The new social story book. Future Horizons.
- Hage, S.R., Lopes-Herrera, S.A., Santos, T.H.F., Defense-Netvral, D.A., Martins, A., Sawasaki, L. Y. & Fernandes, F.D. (2020). Oral hygiene and habits of children with autism spectrum disorders and their families. *Journal of Clinical and Experimental Dentistry*, 12(8), e719.
- Hartley, S.L., Barker, E.T., Seltzer, M.M., Floyd, F., Greenberg, J., Orsmond, G. & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449.
- Head, A.M., McGillivray, J.A. & Stokes, M.A. (2014). Gender differences in emotionality and sociability in children with autism spectrum disorders. *Molecular Autism*, 5(1), 1-9.
- Hoefman, R., Payakachat, N., van Exel, J., Kuhlthau, K., Kovacs, E., Pyne, J., & Tilford, J. M. (2014). Caring for a child with autism spectrum disorder and parents' quality of life: application of the CarerQol. *Journal of Autism and Developmental Disorders*, 44(8), 1933-1945. Available from: <http://dx.doi.org/10.1007/s10803-014-2066-1> (Last accessed: 25 April 2022).

Howlin, P., Goode, S., Hutton, J. & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45(2), 212-229.

Hrdlicka, M., Vacova, M., Oslejskova, H., Gondzova, V., Vadlejchova, I., Kocourkova, J. ... & Dudova, I. (2016). Age at diagnosis of autism spectrum disorders: is there an association with socioeconomic status and family self-education about autism? *Neuropsychiatric Disease and Treatment*, 2016(12), 1639.

Huebner, C. E. & Riedy, C. A. (2010). Behavioral determinants of brushing young children's teeth: implications for anticipatory guidance. *Pediatric Dentistry*, 32(1), 48-55.

IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.

Jaber, M. A. (2011). Dental caries experience, oral health status and treatment needs of dental patients with autism. *Journal of Applied Oral Science*, 19(3), 212-217.

Jacklin, L. (2006). The changing profile of autism in a clinic for children with developmental delay. *Pandagram*, 11(1), 2-3.

Kalyoncu, I.Ö. & Tanboga, I. (2017). Oral health status of children with autistic spectrum disorder compared with non-authentic peers. *Iranian Journal of Public Health*, 46(11);,1591.

Kelly, B., Williams, S., Collins, S., Mushtaq, F., Mon-Williams, M., Wright, B., Mason, D. & Wright, J. (2019). The association between socioeconomic status and autism diagnosis in the United Kingdom for children aged 5–8 years of age: Findings from the Born in Bradford cohort. *Autism*, 23(1), 131-140.

Kim, J. A., Szatmari, P., Bryson, S. E., Streiner, D. L. & Wilson, F. J. (2000). The prevalence of anxiety and mood problems among children with autism and Asperger syndrome. *Autism*, 4(2), 117-132.

King, M. D. & Bearman, P. S. (2011). Socioeconomic status and the increased prevalence of autism in California. *American Sociological Review*, 76(2), 320-346.

Kjelgaard, M. M. & Tager-Flusberg, H. (2001). An investigation of language impairment in autism: Implications for genetic subgroups. *Language and Cognitive processes*, 16(2-3), 287-308.

Klein, U. & Nowak, A.J. (1999). Characteristics of patients with autistic disorder (AD) presenting for dental treatment: a survey and chart review. *Special Care in Dentistry*, 19(5), 200-207.

Klein, U. & Nowak, A. J. (1998). Autistic disorder: a review for the pediatric dentist. *Pediatric Dentistry*, 20, 312-317.

Lai, B., Milano, M., Roberts, M. W. & Hooper, S. R. (2012). Unmet dental needs and barriers to dental care among children with autism spectrum disorders. *Journal of Autism and Developmental disorders*, 42(7), 1294-1303.

Larsson, H. J., Eaton, W. W., Madsen, K. M., Vestergaard, M., Olesen, A. V., Agerbo, E., Schendel, D., Thorsen, P. & Mortensen, P. B. (2005). Risk factors for autism: perinatal factors, parental psychiatric history, and socioeconomic status. *American Journal of Epidemiology*, 161(10), 916-925.

Lauritsen, M. & Ewald, H. (2001). The genetics of autism. *Acta Psychiatrica Scandinavica*, 103(6), 411-427.

Lewis, C., Vigo, L., Novak, L. & Klein, E. J. (2015). Listening to parents: A qualitative look at the dental and oral care experiences of children with autism spectrum disorder. *Pediatric dentistry*, 37(7), 98E-104E.

Linting, M., Meulman, J. J., Groenen, P. J. F., & van der Koojj, A. J. (2007). Nonlinear principal components analysis: Introduction and application. *Psychological Methods*, 12(3), 336-358.

Lofholm, N. (2008). Autism's terrible toll: parents risk "hitting a breaking point". *The Denver Post*. Available from: http://www.denverpost.com/news/ci_11116100?source=rss (Last accessed: 5 March 2022)

Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A. & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of General Psychiatry*, 63(6), 694-701.

Louw, K.A., Bentley, J., Sorsdahl, K. & Adnams, C.M. (2013). Prevalence and patterns of medication use in children and adolescents with autism spectrum disorders in the Western Cape, South Africa. *Journal of Child & Adolescent Mental Health*, 25(1), 69-79.

- Lu, Y. Y., Wei, I. H. & Huang, C. C. (2013). Dental health—a challenging problem for a patient with autism spectrum disorder. *General Hospital Psychiatry*, 35(2), 214-e1.
- Magoo, J., Shetty, A.K., Chandra, P., Anandkrishna, L., Kamath, P.S. & Iyengar, U. (2015). Knowledge, attitude and practice towards oral health care among parents of autism spectrum disorder children. *Journal of Advanced Clinical and Research Insights*, 2(2), 82-86.
- Malow, B.A., Katz, T., Reynolds, A.M., Shui, A., Carno, M., Connolly, H.V. ... & Bennett, A.E. (2016). Sleep difficulties and medications in children with autism spectrum disorders: a registry study. *Pediatrics*, 137(Supplement 2), S98-S104.
- Mansoor, D., Al Halabi, M., Khamis, A.H. & Kowash, M. (2018). Oral health challenges facing Dubai children with Autism Spectrum Disorder at home and in accessing oral health care. *European Journal of Paediatric Dentistry*, 19(2), 127-133.
- Marshall, J., Sheller, B. & Mancl, L. (2010). Caries-risk assessment and caries status of children with autism. *Pediatric Dentistry*, 32(1), 69-75.
- Marshall, J., Sheller, B., Mancl, L. & Williams, B. J. (2008). Parental attitudes regarding behavior guidance of dental patients with autism. *Pediatric Dentistry*, 30(5), 400-407.
- Marshall, J., Sheller, B., Williams, B. J., Mancl, L. & Cowan, C. (2007). Cooperation predictors for dental patients with autism. *Pediatric Dentistry*, 29(5), 369-376.
- Matson, J. L. & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*, 30(6), 1107-1114.
- Maughan, A.L. & Weiss, J.A. (2017). Parental outcomes following participation in cognitive behavior therapy for children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(10), 3166-3179.
- McKinney, C. M., Nelson, T., Scott, J. M., Heaton, L. J., Vaughn, M. G. & Lewis, C. W. (2014). Predictors of unmet dental need in children with autism spectrum disorder: results from a national sample. *Academic Pediatrics*, 14(6), 624-631.
- Murshid, E. Z. (2014). Diet, oral hygiene practices and dental health in autistic children in Riyadh, Saudi Arabia. *Oral Health and Dental Management*, 13, 91-6.

Nagendra, J. & Jayachandra, S. (2012). Autism spectrum disorders: dental treatment considerations. *Journal of International Dental and Medical Research*, 5(2), 118.

Naidoo, M. & Singh, S. (2018). The Oral health status of children with autism Spectrum disorder in KwaZulu-Natal, South Africa. *BMC Oral Health*, 18(1), 165.

Oliveira, A.C.B., Paiva, S.M. & Pordeus, I.A. (2007). Parental acceptance of restraint methods used for children with intellectual disabilities during dental care. *Special Care in Dentistry*, 27(6), 222-226.

Orellana, L. M., Silvestre, F. J., Martínez-Sanchis, S., Martínez-Mihi, V. & Bautista, D. (2012). Oral manifestations in a group of adults with autism spectrum disorder. *Medicina Oral Patologia Oral y Cirugia Bucal*, 17(3), e415.

Oswald, D.P. & Sonenklar, N.A. (2007). Medication use among children with autism spectrum disorders. *Journal of Child and Adolescent Psychopharmacology*, 17(3), 348-355.

Pani, S.C., Mubarak, S.A., Ahmed, Y.T., AlTurki, R.Y. & Almahfouz, S.F. (2013). Parental perceptions of the oral health-related quality of life of autistic children in Saudi Arabia. *Special Care in Dentistry*, 33(1), 8-12.

Rao, T. S. & Andrade, C. (2011). The MMR vaccine and autism: Sensation, refutation, retraction, and fraud. *Indian Journal of Psychiatry*, 53(2), 95.

Reichenberg, A., Gross, R., Sandin, S. & Susser, E.S. (2010). Advancing paternal and maternal age are both important for autism risk. *American Journal of Public Health*, 100(5), 772-773.

Richa, Yashoda, R. & Puranik, M. P. (2014). Oral health status and parental perception of child oral health related quality-of-life of children with autism in Bangalore, India. *Journal of Indian Society of Pedodontics and Preventive Dentistry*, 32(2), 135.

Sanjeevi, J., Jeevanandham, G. & Subhashini, M.H. (2019). Questionnaire of parental perception of general anesthesia in pediatric dentistry. *Drug Invention Today*, 12(2).

Saunders, B. S., Tilford, J. M., Fussell, J. J., Schulz, E. G., Casey, P. H., & Kuo, D. Z. (2015). Financial and employment impact of intellectual disability on families of children with autism. *Families, Systems, & Health*, 33(1), 36-45. Available from:

<http://dx.doi.org/10.1037/fsh0000102> (Last accessed: 2 February 2022).

Sealey, L. A., Hughes, B. W., Sriskanda, A. N., Guest, J. R., Gibson, A. D., Johnson-Williams, L., Pace, D. G. & Bagasra, O. (2016). Environmental factors in the development of autism spectrum disorders. *Environment International*, 88, 288-298.

Seif Eldin, A., Habib, D., Noufal, A., Farrag, S., Bazaid, K., Al-Sharbati, M., Badr, H., Moussa, S., Essali, A. & Gaddour, N. (2008). Use of M-CHAT for a multinational screening of young children with autism in the Arab countries. *International Review Psychiatry*, 20(3), 281 – 289.

Spira, G., & Kupietzky, A. (2005). Oral defensiveness: children with a dysfunction of sensory regulation. *Journal of Clinical Pediatric Dentistry*, 29(2), 119-122.

Springer, P. E., van Toorn, R., Laughton, B. & Kidd, M. (2013). Characteristics of children with pervasive developmental disorders attending a developmental clinic in the Western Cape Province, South Africa. *South African Journal of Child Health*, 7(3), 95-99.

Stein, L. I., Polido, J. C. & Cermak, S. A. (2012a). Oral care and sensory concerns in autism. *American Journal of Occupational Therapy*, 66(5), e73-e76.

Stein, L. I., Polido, J. C., Najera, S. O. L. & Cermak, S. A. (2012b). Oral care experiences and challenges in children with autism spectrum disorders. *Pediatric Dentistry*, 34(5), 387-391.

Teste, M., Broutin, A., Marty, M., Valéra, M.C., Cunha, F.S. & Noirrit-Esclassan, E. (2021). Toothbrushing in children with autism spectrum disorders: qualitative analysis of parental difficulties and solutions in France. *European Archives of Paediatric Dentistry*, 1-8.

Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W. & Brimacombe, M. (2012). The association of autism diagnosis with socioeconomic status. *Autism*, 16(2), 201-213.

Tordjman, S., Somogyi, E., Coulon, N., Kermarrec, S., Cohen, D., Bronsard, G., Bonnot, O., Weismann-Arcache, C., Botbol, M., Lauth, B., Ginchat, V., Roubertoux, P., Barburroth, M., Kovess, V., Geoffray, M., & Xavier, J. (2014). Genex Environment interactions in autism spectrum disorders: role of epigenetic mechanisms. *Frontiers in Psychiatry*, 5, 53.

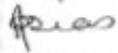
Vajawat, M. & Deepika, P.C. (2012). Comparative evaluation of oral hygiene practices and oral health status in autistic and normal individuals. *Journal of International Society of Preventive & Community Dentistry*, 2(2):,58.

Wakefield, A. J., Murch, S. H., Anthony, A., Linnell, J., Casson, D. M., Malik, M., Berelowitz, M., Dhillon, A. P., Thomson, M. A., Harvey, P., Valentine, A., Davies, S. E. & Walker-Smith, J. A. (1998). RETRACTED: Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *The Lancet*, 351(9103), 637-641.

Werling, D.M. & Geschwind, D.H. (2013). Sex differences in autism spectrum disorders. *Current opinion in neurology*, 26(2), 146.



Appendix 1: Ethical approval from the University of the Western Cape's Research Committee and the Biomedical Ethics Research Committee.

	OFFICE OF THE DIRECTOR: RESEARCH RESEARCH AND INNOVATION DIVISION	Private Bag X17, Bellville 7535 South Africa T: +27 21 959 4111/2948 F: +27 21 959 3170 E: research-ethics@uwc.ac.za www.uwc.ac.za
18 September 2019		
Dr R. Omer		
Faculty of Dentistry		
Ethics Reference Number:	BM19/7/11	
Project Title:	Oral health practices and challenges facing parents of autistic children in the Western Cape.	
Approval Period:	17 September 2019 – 17 September 2020	
I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.		
Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.		
Please remember to submit a progress report in good time for annual renewal.		
The Committee must be informed of any serious adverse event and/or termination of the study.		
		
<i>Ms Patricia Josias Research Ethics Committee Officer University of the Western Cape</i>		
BMREC REGISTRATION NUMBER -130416-050		
FROM HOPE TO ACTION THROUGH KNOWLEDGE		

Appendix 2: Questionnaire: Oral health practices and challenges facing parents of autistic children in the Western Cape (adapted for online version)



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

A. Socio-demographics.

1. What is your relationship to your child?	Biological parent	Foster parent	Adoptive parent	Other	
2. Are you the primary care giver?	Yes	No			
3. How old are you?	Below 20	20-30	30-40	Above 40	
4. How old is your child?	2-4	5-7	8-10	11-12	12 above
5. What is your child's gender?	Male	Female	Other		
6. How many siblings does your child have?	1	2	3	4	More
7. Does the child have any other siblings with Autism?	Yes	No	Unsure		
8. What is your marital status?	Single	Married	Divorced	Widowed	Other
9. What is your (the parent) highest level of education completed?	Unlearned	Primary school	High school	Tertiary education	Additional qualification
10. What is your employment status?	Unemployed	Part-time employment	Full-time employment	Self-employed	Other
11. What is your household's monthly income?	None	R1-2500	R2500 - 5000	R5000 - 10000	+ R10,000

B. Medical History

1. At which age was your child diagnosed with Autism?			
2. Does your child have any other medical condition(s) besides Autism?	Yes	No	
3. If yes, what?			
4. Does your child take medication for Autism?	Yes	No	
5. If yes, what?			

6. Has your child undergone Behaviour Therapy?	Yes	No	
7. If yes, for how long?			
8. Do you think the Behaviour Therapy was beneficial?	Yes	No	
9. Does the child exhibit any self-injurious behaviour?	Yes	No	
10. If yes, describe the behaviour? (E.g. head banging, hair pulling, etc.)			

C. Oral Health practices and challenges at home

1. Does your child clean their teeth?	Yes. child cleans their teeth entirely alone	Yes. I help / assist them to do it	Yes. I supervise them as they clean their teeth	Other	No
2. If no, explain why not?					
3. What method do you / they use to clean their teeth?	Cloth	Brush / toothpaste	Other		
4. If you brush their teeth for them, is it easy to do?	Yes	No			
5. Have you tried a powered / electric toothbrush for your child?	Yes	No			
6. If yes, was the child more cooperative?	Yes	No			
7. How often does the child brush per day?	None	Once	Twice	More	
8. Do they swallow the toothpaste while / after brushing?	Yes	No			
9. Have you ever used a device to keep your child's mouth open?	Yes	No			
10. Does your child floss their teeth?	Yes	No			
11. Do you assist them with flossing?	Yes	No			
12. If yes, is flossing easy to do?	Yes	No			
13. Have you / they tried to use floss holders during flossing?	Yes	No			
14. If yes, was it easier to floss?	Yes	No			
15. Have you tried other methods of plaque control for you child?	Yes	No			
16. If yes, what methods have you tried?	Mouthwashes	Interdental brushes	Tongue scrapers	Other	

17. Have you ever given your child sugar-free gum for tooth decay prevention?	Yes	No			
18. Does your child have any of those oral habits?	Thumb sucking	Tongue thrusting	Lip biting	Mouth breathing	Nail biting
19. Have you tried to stop the habit?	Yes	No			
20. If yes, how?					

D. Oral Health challenges in the clinic

1. Does your child visit the dentist regularly?	Yes	No			
2. If no, why not?					
3. Which dental procedure was done on your child in their last visit?	Regular check-up	Cleaning	Filling	Extraction	Other
4. At which dental treatment facility do you usually receive treatment?	Community clinic	Private clinic	Tertiary institution		
5. How would you describe your child's experience during that session?	Positive	Neutral	Negative	Unsure	
6. How does your child usually respond at the dentist?	Cooperative	Neutral	Uncooperative	Unsure	
7. Does your child's behaviour change at the dentist?	Yes	No	Unsure		
8. If yes, in what way does it change?					
9. What does your child complain of most when visiting the dentist?	Lying down on the chair	Drilling sounds	Chair light	Sharp instruments	Putting something in their mouth
10. Does your child's behaviour discourage you from visiting the dentist?	Yes	No			
11. Has your child received any Behaviour Shaping attempts in the dental clinic such as:					
A. Adhering to the same appointment/same dentist	Yes	No			
B. Social story (stories designed to help Autistic children to prepare for social interaction in specific events, e.g. visiting the dentist)	Yes	No			
C. Modelling with peers (peers of the same age and sex to	Yes	No			

demonstrate for positive behaviours)					
D. If you answered yes to any of the above, was it beneficial?	Yes	No			
12. Have you ever had your child physically restrained to complete dental treatment?	Yes	No			
13. Has your child previously undergone dental treatment under general anaesthesia/ sedation?	Yes	No			
14. Do you prefer that your child's dental treatment be completed after putting them to sleep (i.e. under general anaesthesia / sedation)?	Yes	No			
15. Do you feel that you don't have enough time to take care of the child's oral health?	Never	Rarely	Sometimes	Often	Always
16. Do you feel that the cost of dental treatment is a barrier to taking your child to the dentist?	Never	Rarely	Sometimes	Often	Always
17. Have you ever experienced difficulties trying to find a dentist who was willing to treat you child?	Never	Rarely	Sometimes	Often	Always
18. What additional support do you feel you need from Oral Health Professionals in order to provide adequate dental treatment for your child?					
19. Do you feel that dental Oral Health Professionals are adequately trained / prepared to manage Autistic children during dental visits?	Yes	Sometimes	No	Unsure	