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Improving Access and Reducing Barriers to Dental Care for Children with Autism Spectrum Disorder

Siobhán Maria Barry

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others

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Dedication

to Peter James Barry,

for his neverending support and patience.

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Abstract

Introduction: Autism Spectrum Disorder (ASD) is a pervasive developmental disorder, defined as a syndrome consisting of abnormal development of social skills with limitations in the use of interactive language. Anecdotal evidence suggests that parents/carers of children with ASD have difficulty in accessing dental care for their children.

Aims: This study examined the problems encountered by children with ASD, when accessing dental care.

Methods: This was a cross-sectional, case-control questionnaire study. A piloted questionnaire was developed to identify the main barriers to dental care experienced by patients with ASD in Hull and East Riding. The study group was comprised of parents/carers of children with ASD, and the control group was comprised of parents/carers of age matched healthy, neurotypical children. Results were analysed using Chi-Square and Fisher's Exact tests where appropriate. Significance was deemed at $p < 0.05$. Ordinal data was presented using medians and 25th and 75th centiles and compared using Mann Whitney U test.

Results: 112 subjects completed the questionnaire. There was no significant difference in accessing dental care between study and control groups ($p = 0.051$), although access was perceived as more difficult in the ASD group ($p < 0.001$). There was a significantly greater perceived difficulty in travelling to the dental surgery in the ASD group. Predicted negative behaviours were more frequent in the ASD group. All suggested interventions were predicted to be helpful in a significantly greater proportion of the ASD group. An introductory package was put into place using these results.

Conclusion: This research has allowed a unique insight into the potential barriers to dental care for children with ASD from the perspective of their parents/carers, and allowed the production of an intervention, to help to overcome some of these barriers. It is hoped that this intervention will improve the dental experience for this vulnerable group of children and their parents/carers.

Table of Contents

	Page
Acknowledgements	IV
Abstract	V
Table of Contents	VII
List of Tables	XIV
List of Figures	XV
List of Abbreviations	XVII
1.0 Introduction	1
2.0 Literature Review	3
2.1 Definition of autism spectrum disorder	3
2.2 Phenotypes of autism spectrum disorder	3
2.2.1 Autism	3
2.2.2 Pervasive Developmental Disorder – Not Otherwise Specified	4
2.2.3 Asperger’s Disorder	4
2.2.4 Rett Disorder	5
2.2.5 Childhood Disintegrative Disorder	5

2.2.6 Changes to the ASD Classification	6
2.3 Diagnosis	6
2.3.1 Age at Onset	6
2.3.2 Qualitative Impairment in Social Reciprocity	7
2.3.3 Qualitative Impairment in Communication	8
2.3.4 Restricted Repertoire of Behaviour, Interests and Activities	9
2.4 Prevalence of ASD	9
2.5 Aetiology – Genetic	10
2.6 Aetiology - Environmental	12
2.7 Behaviour	14
2.8 Intellect	15
2.9 Medical Co-Morbidities	15
2.9.1 Macrocephaly	15
2.9.2 Iron Deficiency Anaemia	16
2.9.3 Epilepsy	16
2.9.4 Abnormal Sleeping Pattern	17
2.9.5 Constipation	18

2.10 Psychiatric Co-Morbidities	18
2.11 Prognosis	20
2.12 Dental Problems	21
2.12.1 Dental Caries	21
2.12.2. Dental Erosion	23
2.12.3 Dental Trauma	24
2.12.4 Oral Effects of Systemic Medication	24
2.13 Barriers to Dental Care	24
2.13.1 Access to Dental Care	25
2.13.2 Behaviour in the Dental Surgery	27
2.13.3 Culture and Language	30
2.13.4 Late Diagnosis	30
2.13.5 Difficulty in Accessing Specialist Dental Care	30
2.13.6 Co-Morbidities	31
2.13.7 Barriers to Medical Care	32
3.0 Aims	34
4.0 Hypothesis	34

5.0 Study Design	35
5.1 Primary Investigator	35
5.2 Initial Study Population	35
5.3 Study Group	36
5.4 Control Group	38
5.5 Inclusion Criteria	39
5.6 Exclusion Criteria	39
5.7 Subject Withdrawal Criteria	40
5.8 Consent	40
5.9 Storage of Participant's Personal Data	42
5.10 Patient Identifiable Data	42
5.11 Questionnaire	42
5.12 Statistics	44
5.13 Indemnity	46
5.14 Monitoring and Audit of Research	46
5.15 Ethics Application	46
5.15.1 Dental Research Ethics Committee (DREC)	47

5.15.2 National Research Ethics Committee (NRES)	47
5.15.3 Research and Development	49
5.16 Potential Benefits for the Study Group	50
5.17 Potential Benefits of the Control Group	51
5.18 Potential Risks and Burdens for Study and Control Group Participants	51
6.0 Results	52
6.1 Pilot Study	52
6.2 Results of the Main Study	54
6.2.1 Attendance at Dental Services	55
6.2.2 Transport to Dental Services	58
6.2.3 Inside the Dental Surgery	59
6.2.4 Strategies for Accessing the Dental Surgery	60
6.2.5 Appointment Time	60
6.2.6 Behaviour of Children	60
6.2.7 The Dental Surgery	63
6.2.8 Dental Pain and Communication	64

6.2.9 Strategies for Improving Dental Attendance	64
6.2.10 Frequency of Dental Visitation	65
6.2.11 Any Other Thoughts or Ideas about Difficulties your Child May Experience while visiting the dentist?	66
7.0 Discussion	87
7.1 Pilot Study	87
7.2 Main Study	88
7.2.1 Attendance at Dental Services	89
7.2.2 Transport to Dental Services	92
7.2.3 Inside the Dental Surgery	93
7.2.4 Strategies for Accessing the Dental Surgery	95
7.2.5 The Dental Surgery	108
7.2.6 Dental Pain and Communication	111
7.2.7 Strategies for Improving Dental Attendance	114
7.2.8 Frequency of Dental Visitation	116
7.2.9 Appointment Time	116

7.2.10 Any other thoughts or ideas about difficulties your child may experience while visiting the dentist	117
7.2.11 Limitations of the study	119
8.0 Intervention	125
10.0 Null Hypothesis Rejection	128
11.0 Further Research	128
12.0 Conclusion	129
List of References	130
Appendices	XX

List of Tables

		Page
Table 1	Basic Demographics of study participants	71
Table 2	Analysis of number of subjects who experienced difficulty in travelling to the dentist according to method of transport	71
Table 3	Analysis of preferred appointment times for all subjects	71
Table 4	Analysis of predicted behaviours in ASD group	72
Table 5	Analysis of activities predicted to be tolerated by all subjects	72
Table 6	Analysis of methods of communication utilised in ASD group	72
Table 7	Analysis of number of respondents who responded favourably to proposed interventions	73
Table 8	Analysis of frequency of preferred recall intervals	73

List of Figures

		Page
Figure 1	Results of Pilot Study	53
Figure 2	Comparison of attendance at dental services, according to diagnosis	74
Figure 3	Comparison of expressed difficulty in attending dental services, according to diagnosis	75
Figure 4	Comparison of difficulty of attending dental services using private transport, according to diagnosis	76
Figure 5	Comparison of difficulty attending dental services using public transport, according to diagnosis	77
Figure 6	Comparison of need to park close to the dental clinic, according to diagnosis	78
Figure 7	Comparison of anticipated difficulty in waiting room, according to diagnosis	79
Figure 8	Comparison of anticipated greater difficulty in attending if waiting room was busy, according to diagnosis	80
Figure 9	Comparison of anticipated helpfulness of strategy of parents/guardians phoning the dental clinic prior to arrival, to facilitate immediate entry into the dental clinic, according to diagnosis	81
Figure 10A	Comparison of favourable appointment times, according to diagnosis – preferences for the first appointment in the morning	82
Figure 10B	Comparison of favourable appointment times, according to diagnosis – preferences for a mid morning appointment	83

Figure 10C	Comparison of favourable appointment times, according to diagnosis – preferences for first appointment post lunch	84
Figure 10D	Comparison of favourable appointment times, according to diagnosis – preferences for an appointment in mid afternoon	85
Figure 10E	Comparison of favourable appointment times, according to diagnosis – preferences for a late afternoon appointment	86

List of Abbreviations

ASD	Autism Spectrum Disorder
NICE	National Institute for Health and Clinical Excellence
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise specified
TDO2	Tryptophan 2,3 Dioxygenase
GABRB3	Gamma-Amino-Butyric Acid Subunit Beta-3
GABRA5	Gamma-Amino-Butyric Acid Subunit Alpha-5
NLGN3	Neurolingin 3
NLGN4	Neurolingin 4
BDNF	Brain Derived Neurotrophic Factor
DRD3	Dopamine-3-Receptor Gene
SNP	Single Nucleotide Polymorphisms
MMR	Measles, Mumps, Rubella Vaccination
USA	United States of America
GMC	General Medical Council
IQ	Intelligence Quotient
GI	Gastrointestinal
dmft/DMFT	Decayed, Missing and Filled Teeth
AAPD	American academy of Paediatric Dentistry
DHHS, HRSA, MCHB	Department of Health and Human services, Health Resources and Services Administration, Maternal and Child Health Bureau
UK	United Kingdom
NHS	National Health Service
SpR	Specialist Registrar
CHCP	City Healthcare Partnership

DREC	Departmental Research Ethics Committee
NRES	National Research Ethics Committee
IRAS	Integrated Research Application System
PALS	Patient Advice and Liaison Service
R&D	Research and Development
SSI	Site Specific Information
PECS	Picture Exchange Communication System
ABA	Applied Behaviour Analysis
CLAP	Cleft Lip and Palate
CP	Cerebral Palsy
GDPs	General Dental Practitioners
GA	General Anaesthetic

**Improving Access and Reducing Barriers to
Dental Care for Children with Autism Spectrum
Disorder**

1.0 Introduction

The term “autism” is a derivation of the Greek word “auto” and means self or same (Braff and Nealon, 1979). Jean-Marc-Gaspard Itard is credited with the first description of what may have been an autistic child, in his account of the so-called “Wild Boy of Aveyron”. Itard attempted to categorically differentiate between autism and mental retardation in his 1928 memoir, entitled “Mutism as produced by a lesion of the intellectual functions” (Carrey, 1995).

The term autism was first described in 1919 by the famous Swiss psychiatrist Eugen Bleuler, who coined the phrase to describe the striking social impairment of schizophrenia (Parnas et al., 2002). Bleuler described this schizophrenic autism as a “detachment from reality with the relative and absolute predominance of the inner life” (Parnas et al., 2002). Eugene Minkowski, the French psychiatrist who introduced Bleuler to French audiences considered autism not so much a “withdrawal to fantasy” as an expression of “lack of vital contact with any reality” (Minkowski, 1927). The term was borrowed from its Bleulerian origin in 1943 by the Austrian psychiatrist and physician, Dr Leo Kanner from Johns Hopkins University (Kanner, 1943; Crespi, 2010). Kanner described a group of 11 children who shared the common symptoms of “the inability to relate themselves in the ordinary way to people and situations from the beginning of life”, and “an extreme autistic aloneness”. He theorised that these children are born with an “innate inability to form the usual, biologically provided affective contact with people”.

Simultaneously, the Austrian paediatrician, Dr Hans Asperger described Asperger syndrome, often considered the uppermost level of the autistic spectrum (Backman and Pilebro, 1999a).

Understanding of autism has since evolved and autism spectrum disorders have become recognised as a group of lifelong, neurodevelopmental disorders with severe impairment of social reciprocity, communication and behaviour. These disorders, also termed “pervasive developmental disorders”, include autism (early infantile autism or Kanner’s autism), pervasive developmental disorder – not otherwise specified, Asperger disorder, Rett disorder and childhood disintegrative disorder (American Psychiatric Association, 2000).

2.0 Literature Review

In reviewing the literature on autism spectrum disorder, its definition, phenotypes, prevalence, aetiology, clinical features, co-morbidities and possible barriers to dental care will be discussed.

2.1 Definition of Autism Spectrum Disorder

The term autism spectrum disorders (ASD) is described as “ the behavioural characteristics of a group of children, young people and adults with qualitative abnormalities in reciprocal social interaction and in patterns of communication, and by a restricted, stereotyped and repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual’s functioning across a range of situations although they may vary in level of severity” (NICE draft guidelines, 2011).

2.2 Phenotypes of Autism Spectrum Disorder

2.2.1 Autism

Kanner’s autism is often referred to as “classic autism” and is the best known and most severe of the pervasive developmental disorders (Klin, 2006). Autistic patients present with a classic triad of impairments – a qualitative impairment in social reciprocity, qualitative impairment in communication and a stereotypical, restricted repertoire of behaviour, interests and activities. These symptoms become evident before the age of three years (American Psychiatric Association, 2000).

2.2.2 Pervasive Developmental Disorder – Not Otherwise Specified (PDD NOS)

Pervasive developmental disorder – not otherwise specified is a sub-threshold diagnosis within the autistic spectrum. It is categorised as a pervasive impairment in social behaviour or communication, or the presence of a stereotypical repertoire of behaviours, interests or activities, but the diagnostic criteria are not met for pervasive developmental disorder, schizophrenia, schizotypal personality disorder or avoidant personality disorder. This classification includes “atypical autism” - those patients who demonstrate atypical presentation, threshold presentation or late onset of symptoms (American Psychiatric Association, 2000).

2.2.3 Asperger’s Disorder

Asperger’s disorder involves a diagnosis of qualitative impairment in social interaction, a stereotypical and restricted pattern of behaviour with significant impact on social or occupational functioning. However, patients with Asperger’s syndrome do not present with impaired language development and intellectual skills are preserved (American Psychiatric Association, 2000). Intensive, restrictive interests, clumsiness, a paucity of nonverbal communication and pleonastic monologues are characteristic (Klin, 2006).

2.2.4 Rett Disorder

Rett disorder became recognised as a distinct entity following a seminal paper by Hagberg et al. (1983). It is an x-linked dominant disorder, with almost female exclusivity and male hemizygous lethality. Affected patients show normal psychomotor development up to the age of 7-18 months, with a subsequent dramatic, progressive encephalopathy followed by rapid neurological decline. Deceleration of head growth, dementia, autistic features, loss of purposeful hand movements and characteristic, stereotypical hand movements typify this disorder (Hagberg et al., 1983). More recently, mutations in the gene MECP2, encoding x-linked methyl-CpG-binding protein 2 have been identified as the aetiology of some cases of Rett disorder (Amir et al., 1999).

2.2.5 Childhood Disintegrative Disorder

Childhood disintegrative disorder is a rare disorder characterised by a distinctive developmental regression following a period of apparently normal development, as defined by age-appropriate behavioural, communication, verbal and social interaction skill (American Psychiatric Association, 2000). It is differentiated from autism by the specification of at least two years of normal development prior to onset of regression (Goldberg et al., 2003). Frequently, when the child has developed age-appropriate skills such as appropriate speech, or toilet training, the sudden loss of these skills, for example becoming totally silent or incontinent represents a dramatic metamorphosis, causing significant concern to parents/carers (Homan et al., 2011)

2.2.6 Changes to the ASD Classification

The Diagnostic and Statistical Manual of Mental Disorders, fifth edition interim report has addressed several contentious issues regarding the classification of ASD (Szatmari, 2011). In the first instance, the term “pervasive developmental disorder” is to be replaced with the more ubiquitous term “autism spectrum disorder”. Secondly, the various subdivisions within the term “autism spectrum disorder” including Asperger’s disorder and pervasive developmental disorder-not otherwise specified will be abolished. This aims to reduce the clinical resources used to establish an accurate diagnosis within the ASD spectrum, and to obviate disagreements regarding said diagnosis (Szatmari, 2011).

2.3 Diagnosis

The diagnosis of autism is based on four criteria: onset prior to the age of three, qualitative impairment of social interaction, severe abnormality of communication and restricted, repetitive and stereotypical patterns of behaviour, interests and activities (American Psychiatric Association, 2000). Currently, if the patient’s symptoms correlate with the diagnostic criteria for Rett disorder or any other disorder on the ASD spectrum, this will take priority over autism (Klin, 2006).

2.3.1 Age at Onset

The diagnostic signs of autism manifest before the age of three years, but parents usually express concern between the ages of one year to eighteen months. These concerns may involve a fear of deafness, due to lack of response to verbal stimuli, or inappropriate response to normal household

sounds, such as the vacuum cleaner (Klin, 2006). It has been shown that 33% of autistic children demonstrate normal or near normal communication and social skill development in the first one to two years of life, with subsequent regression referred to as “early autistic regression” (Werner and Dawson, 2005). Osterling and Dawson (1994) demonstrated autistic characteristics in eleven children, following a retrospective viewing of their videoed first birthday parties. These children, who were subsequently diagnosed with autism, were compared with eleven typically developing children. The autistic children demonstrated decreased attraction to the faces of other people and a decreased likelihood to interact with other people or orientation to name. Although a reported fifty percent of parents have noticed abnormalities in development before the age of one year (Ornitz et al., 1977), this diagnosis is confounded by the inconsistency of parental perception and reporting of these symptoms (Goldberg et al., 2003). Overall, diagnosis of ASD can be unacceptably late. Oslejskoaá et al. (2007) have reported the mean age at diagnosis for children with ASD is 81.5 months, which represents an average diagnostic delay of 51 months. This delays referral to the appropriate support services.

2.3.2 Qualitative Impairment in Social Reciprocity

The developing infant graduates selectively towards a smiling face or loud voice, but the autistic child pays little attention to social stimuli. The usual interactive games of infancy may be completely ignored and play skills may be conspicuous by their absence (Klin, 2006). Facial recognition is an integral aspect of social functioning, allowing the identification of family, friends and enemies. Evidence suggests that individuals with autism demonstrate atypical

visual processing, manifesting as abnormalities in facial perception (Deruelle et al., 2004). However, this deficit appears to be limited to a selective impairment of facial recognition rather than a more widespread problem with object perception (Schultz, 2005).

2.3.3 Qualitative Impairment in Communication

Delayed or unusual language development is a common manifestation in the autistic child, with a 30% risk of complete lack of speech (Klin, 2006). The development of linguistic ability shows a broad diversity within the ASD spectrum. Marked language delay is the most common finding within this group, with significant reduction in the expected language reception over expression advantage. Young children with ASD have been shown to exhibit more profound receptive than expressive language delay (Ellis et al., 2010). Children with ASD can be non-verbal and those who can speak do not use language properly and often demonstrate immediate or delayed echolalia (the involuntary, parrot-like repetition of a word or phrase) (Saad and Goldfeld, 2009). The speech pattern is characteristically monotone and irrelevant to time or place, with the pronoun "I" rarely being used (Swallow, 1969).

Play patterns form an important early indicator of the development of language and social skills. Christensen et al. (2010) discovered deficiencies in play in children as young as 18 months, who were later diagnosed with ASD.

The concept of developmental regression, particularly in the area of language development is widely accepted, and is strongly associated with ASD (Rutter, 2011).

2.3.4 Restricted Repertoire of Behaviour, Interests and Activities

The autistic child frequently demonstrates a preference for routine, often becoming distressed if change is introduced (Klin, 2006). Literature has described a tendency to repetitive behaviour such as spinning (Bracha et al., 1995). Tactile defensiveness may be exhibited, manifesting as a disproportionate response to non-noxious stimuli, such as certain fabrics. Alternatively, the child may display a heightened pain threshold, with seeming lack of distress following injury (Klin, 2006).

2.4 Prevalence of ASD

Leo Kanner did not estimate a prevalence of ASD in his seminal paper (Kanner, 1943). However, over 20 years later, Lotter used the diagnostic criteria of Kanner in his 1966 epidemiological study of autistic conditions. This research involved the assessment of all 8-10 year old children within the county of Middlesex in the UK, and proposed a prevalence of 4.5 per 10,000 (Lotter, 1966). Wing and Gould (1979) reported an overall prevalence of 21.2 per 10,000 following assessment of children under the age of 15 in London. A high prevalence of ASD has been noted in children with developmental delay (Gillberg et al., 1986). More recently, the prevalence has been shown to be 5.5 – 5.7 per 1000, with a male: female ratio of 4:1 and appears to be unrelated to race, socioeconomic status or parental education (Friedlander et al., 2006; Swallow, 1969). Present estimates suggest an increased prevalence of ASD of 1:88 children (11.3 per 1000), based on eight-year-old children in fourteen different areas of the United States of America. This represents a 23% increase since 2009 and a 78% increase since 2007 (Centres for Disease Control and Prevention, 2012). It has been theorised that the increased incidence of ASD

over time can be attributed to both improvements in diagnostic expertise and a widening of the ASD parameters (Rutter, 2005).

2.5 Aetiology – Genetic

The aetiology of autism is not clear, but it is thought to be multifactorial with both genetic and environmental influences (Zhang et al., 2010). Evidence from twin studies suggests a genetic predisposition with involvement of chromosomes 2,7,15,16 and 19. An X-linked component could explain the male excess (Jamain et al., 2003).

Abnormality of serotonin levels is the most frequent biochemical finding in patients with ASD (Nishimura et al., 2007). Tryptophan 2,3 dioxygenase (TDO2) is the rate-limiting enzyme in the formation of tryptophan – the precursor of serotonin. Mutations, which result in alteration of its activity, have been implicated in the aetiology of autism (Nabi et al., 2004). It has been postulated that mutations associated with gamma-amino-butyric acid subunit beta-3 (GABRB3), gamma-amino-butyric acid subunit alpha-5 (GABRA5), neuroligin 3 (NLGN3) and neuroligin 4 (NLGN4) are common across the autistic spectrum (Belmonte et al., 2004). Cheng et al. (2009) have suggested an association between brain derived neurotrophic factor (BDNF) polymorphism and autism, due to the trophic effect of BDNF on the serotonergic system. Interestingly, recent research by Staal et al. (2011) has identified polymorphism of the dopamine-3-receptor gene (DRD3) as having a protective effect against a certain type of repetitive behaviour (insistence on sameness).

Breech presentation, low Apgar score, parental psychiatric history (Larsson et al., 2005), increased bleeding during pregnancy (Brimacombe et al., 2007), daily smoking in early pregnancy and caesarean delivery (Hultman et al., 2002) have been linked to autism. A recent study has shown an association between ASD and increasing paternal age, with a 5.75 times increased risk of autism for children of men aged 40 or older compared with offspring of men aged 30 or younger (Reichenberg et al., 2006). Disordered porphyrin metabolism has been detected in autistic children, as evidenced by increased urinary porphyrin levels, although the mechanism responsible remains unknown (Woods et al., 2010). Magnetic resonance imaging studies have revealed abnormalities in the limbic system of some autistic children. These are areas of the brain, which are associated with social behaviour and emotion (Schumann et al., 2004). It had been thought that children with autistic spectrum disorder exhibit impairment in the recognition of various emotions. Recent research by Tracy and Robins (2010) however, found no such disparity between high functioning autistic children and a neurotypical control group. This in turn has led to suggestions that if autistic children use a more deliberate system to identify emotions, they become competent at doing so quickly. This has not been established and the generalisation of this work is potentially problematic as the study group was composed exclusively of high-functioning children in an older age category (Tracy and Robins, 2010). ASD has been linked to a number of genetic syndromes such as William's syndrome (Reiss et al., 1985), Duchenne muscular dystrophy (Komoto et al., 1984) as well as to metabolic disorders such as phenylketonuria (Lowe et al., 1980).

Compelling support for a genetic aetiology for ASD is the increased sibling recurrence risk of 4.5% (Jorde et al., 1991). This risk is related to severity of

learning disability, with a recurrence risk of 5.5% when intelligence quotient (IQ) is less than 50, and falls to 3.9% with an increased IQ of greater than or equal to 50 (Jorde et al., 1991).

Single Nucleotide Polymorphisms (SNP), are genetic markers which assist the identification of genes related to various diseases. Recent work by Jiao et al. (2012) suggests promising results by utilising SNP to predict symptom severity in ASD.

2.6 Aetiology - Environmental

Neurotoxic effects on the developing brain involving heavy metals such as mercury and lead, particularly during the prenatal period, have been postulated as a plausible aetiology for ASD (Geier et al., 2010). The developing brain is at risk due to the extended time period over which neuronal development occurs. Moreover, heavy metals are not filtered by the placenta, and therefore have unhindered access to the developing neural cells (Costa et al., 2004). Bernard et al. (2001) highlighted the similarities in biological presentation between ASD and mercury poisoning, and used the history of acrodynia to suggest an aetiological role for mercury in the pathogenesis of ASD. The source of mercury was theorised to arise from thimerosal - a mercury containing preservative in childhood vaccines. However this association is not supported by recent research (Schultz, 2010). Thimerosal has been mostly but not completely withdrawn from childhood vaccines since 2004 (Adams et al., 2007). An ecological association between ASD and environmental mercury release in Texas was recently reported (Palmer et al., 2006), and a 2007 study revealed that children with autism presented with a 2.1 fold increased levels of mercury in exfoliated primary teeth (Adams et al., 2007). Children with ASD have

abnormal levels of glutathione (Herbert, 2010), which binds mercury prior to its excretion (Adams et al., 2007). Also, oral antibiotics have been shown to almost eliminate mercury excretion, through reduction in gut flora (Rowland, 1984). High mercury levels in this research were attributed to increased use of oral antibiotics during the first three years of life, compounded by lower than average glutathione levels in children with ASD (Adams et al., 2007). However, recent research, investigating the levels of heavy metals in the exfoliated teeth of children with ASD has not found such an effect (Abdullah et al., 2012).

Fluoride has been described as a neurotoxin, along with cadmium and aluminium, and all have been implicated in the aetiology of ASD (Blaylock, 2009).

Andrew Wakefield caused considerable controversy following his 1998 publication, "Ileal-Lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children" (Wakefield et al., 1998), in which he suggested a link between the measles, mumps and rubella (MMR) vaccination, chronic enterocolitis and developmental regression. This study has been criticised for its methodological flaws, including the small study number (n=12) and uncontrolled design, as well as for its highly unsubstantiated conclusions (Rao and Andrade, 2011). As a result of this study, uptake of the MMR plummeted in the UK, falling from 91% in 1997-1998 to 80% in 2003-2004. The resultant loss of herd immunity from measles led to an increase in measles incidence from 2002 (Murphy, 2011). The impact of this research was also felt in the United States of America (USA), as it compounded unsubstantiated fears regarding the link between thimerosal and ASD (Leask et al., 2010).

Wakefield's research was conclusively refuted, in the work of Honda et al. (2005). This group looked at the incidence of ASD diagnosis pre and post withdrawal of the MMR vaccine in Japan, and found no evidence of a decline following the cessation of the vaccination regime.

The Lancet has retracted Wakefield's article following a ruling by the general medical council (GMC) in January 2010 that Wakefield had breached the constraints of the ethical committee approval for his research, and had failed to disclose conflicts of interest (Dyer, 2010).

2.7 Behaviour

Patients with ASD show considerable heterogeneity (Marshall et al., 2007) with milder forms being more common than classic autism. Patients with ASD can show a broad range of behaviour from seeming withdrawn and avoiding eye contact, to making eye contact, smiling and hugging. It is important to note that this interaction is usually on the child's own terms and not easily elicited by others (American Academy of Pediatrics, 2001). Aggression, temper tantrums, psychiatric disturbance and limited attention span are common features of the condition (Loo et al., 2009). It has been reported that maternal stress levels are higher than in mothers of typically developing children or mothers of children with developmental delay (Weiss, 2002). Some authors have suggested a higher risk of divorce in parents of children with ASD than matched controls (Hartley et al., 2010), but more recent work has found no such results (Freedman et al., 2012). This finding may be explained by the supportive services offered to individuals with ASD and their families (Freedman et al., 2012).

The literature also suggests that patients with ASD are at high risk of bullying by their peers, with a two-fold increased risk than in the general population (Cappadocia, 2012).

2.8 Intellect

Intellect in autistic patients ranges from severe learning disability to above average intelligence, although intelligence quotient (IQ) is not a defining feature of autism (Rapin, 1999). The prevalence of learning disability in children with ASD has been shown to be as high as 60% (Charles, 2010). Some children can show excellence in one particular area such as music or mathematics (American Academy of Pediatrics, 2001).

2.9 Medical Co-Morbidities

Medical problems are common in the child with ASD and may be multiple (Rada, 2010). It has recently been shown that children with ASD are more likely to utilise healthcare than controls, and incur a significantly higher healthcare expenditure (Croen et al., 2006).

2.9.1 Macrocephaly

Macrocephaly has been extensively documented in the patient with ASD, which appears to be unrelated to seizure disorders or IQ (Woodhouse et al., 1996). This increased head circumference is not present at birth, but abnormal regulation of brain growth in the early years results in cerebellar white matter, neocortical grey matter and cortical white matter overgrowth (Courchesne et al.,

2001). Recent research has confirmed this abnormal cortical developmental progression (Mak-Fan et al., 2012). Pagani et al. (2012) have shown increased blood flow involving the limbic, posterior associative, visual and cerebellar cortices, which lends further credence to a neurobiological defect of ASD. The excessive brain size at two to three years may be the result of excessive neuronal growth, or amplification of axonal connections (Courchesne et al., 2001). The abnormal neuronal growth tends to level off during middle childhood, but a small number of patients with ASD may exhibit macrocephaly, which persists into adulthood (Rutter, 2011). Importantly, this unusual and distinctive pattern of increased brain size may provide a marker for the identification of patients with ASD, prior to the onset of clinical signs (Courchesne et al., 2003).

2.9.2 Iron Deficiency Anaemia

A high incidence of iron deficiency has been noted in children with ASD, and it is recommended to undertake routine haematological investigation for these patients (Hergüner et al., 2012).

2.9.3 Epilepsy

It is well accepted that up to a quarter of patients with ASD develop epilepsy (Rutter, 2011). This represents a 22 fold increased risk when compared with the general population, and has been shown to be negatively associated with IQ (Volkmar and Nelson, 1990).

2.9.4 Abnormal Sleeping Pattern

The disturbance of normal sleeping patterns can cause considerable distress to the parents of children with ASD (Reynolds and Malow, 2011). Oyane et al. (2005) have recently demonstrated a high prevalence of sleep disorders (80%) in children with ASD. These disorders included a shorter sleeping time and a low sleep efficiency. They did not, however, report any evidence of early morning awakening. This disruption can affect both high and lower functioning children, prove extremely difficult to manage and adversely affect behaviour (Charles, 2010). Occasionally, this sleep disturbance may be linked to a medical co-morbidity such as obstructive sleep apnoea or gastro-oesophageal reflux disease (Charles, 2010).

It has been suggested that children with autism may be at higher risk than the general population for obesity, due to a decreased tendency to partake in activities and increased time engaged in sedentary pastimes such as playing computer games. However, it has recently been established that patients with ASD have a similar prevalence of obesity as children in the general population (Curtin et al., 2005). Children with ASD frequently follow a limited diet, often exhibiting a preference for soft foods (Schreck et al., 2004). Sweets may often be used as a reward for improved behaviour, and parents should be advised to change to alternative treats such as favourite activities, both to reduce risk of dental caries and obesity (Charles, 2010). Marshall et al. (2010) ascertained that 44% of children with ASD had a history of receiving food as a reward for positive behaviour, and of these, 46% received sweet rewards. They found a lower incidence of new carious lesions in those individuals who preferred crunchy foods (14%), compared with those who did not (43%) although the

relationship between dental caries and food rewards was not statistically significant.

2.9.5 Constipation

Constipation has been shown to be a significant co-morbidity in the child with ASD. Pang and Croaker (2011) reported that 25% of children attending a constipation clinic in Glasgow had a diagnosis of ASD. While often assigned a behavioural aetiology in the typically developing child (Youssef and Lorenzo, 2001), there may be an inherent gastro-intestinal anomaly in the child with ASD (Pang and Croaker, 2011). Recent studies have discovered genetic abnormalities in the MET tyrosine kinase gene, which co-regulates gastrointestinal (GI) and brain functions (State, 2006).

2.10 Psychiatric Co-Morbidities

Psychiatric co-morbidities are common, may be multiple and can be detrimental to function (Mattila et al., 2010). Studies have shown a high prevalence of psychiatric disorders in the ASD population (70%), with a 41% prevalence of multiple disorders (Simonoff et al., 2008). There is evidence that up to 40% of patients with ASD will develop an anxiety disorder (van Steensel et al., 2011). A recent study demonstrated a 16% incidence of novel psychiatric diagnoses in adult life, in patients with ASD (Hutton et al., 2008). However, a wide variation in psychiatric status was recorded, from absence of new psychiatric impairment to recurrent psychiatric episodes.

Physical self-stimulation is common and can include arm flapping, head banging, rocking and picking or poking the oral mucosa with the fingernails.

Self-injurious behaviour in autistic patients has been extensively documented in the literature. It has been estimated that 70% of autistic patients may exhibit self-injurious behaviour (Howlin, 1973). Toe walking can occur and may be an attempt by the child to reduce contact with the floor (American Academy of Pediatrics, 2001). Repetitive behaviours such as excessive straightening of furniture in a room (Kuhn et al., 2009) or pica (McAdam et al., 2004) can manifest in autistic children. Medina et al. (2003) noted factitious ulceration and the self-extraction of primary teeth along with succedaneous tooth buds, in a four-year-old autistic girl.

A high prevalence of extremely challenging behaviour has been noted anecdotally, in autistic teenagers. This challenging behaviour is less frequently seen in older cohorts. This phenomenon has been linked to an increased body size and strength as children get older, which can lead to more dangerous behaviour, the possible emergence of new behaviours at this time, or the shorter life expectancy of those with more severe disabilities. It has been shown that challenging behaviours correlate well with reduced communication and social skills in children with ASD, but have been shown to reduce with time (Murphy et al., 2005).

It has been reported that 45% of children with ASD are managed with psychotropic medications (Charles, 2010; Robb, 2010). Those who exhibit externalising behaviours such as agitation or aggression are most often managed using alpha-agonists (Clonidine), or neuroleptic drugs. Neuroleptic drugs are divided into typical and atypical categories. The newer, atypical neuroleptic drugs such as risperidone show lower incidence of extrapyramidal side effects (Charles, 2010). It is well documented that autistic individuals show a unique resistance to the effects of psychotropic medications, particularly in

relation to fundamental symptoms of impaired communication and social skills. The reason for this is unclear, but it may be that the ASD defect does not pertain to neurotransmitters (Rutter, 2011).

Some behavioural disturbances can respond to the mood-regulating effects of anti-epileptics, while behaviour such as depression can be managed with selective serotonin re-uptake inhibitors (SSRIs). It is important to note that children with ASD frequently take medications to manage medical co-morbidities and these medications may be multiple.

2.11 Prognosis

The long-term prognosis for children with ASD involves the persistence of impairments throughout life, although, as previously stated, there may be an improvement in communication and social behaviour over time (Szatmari et al., 2003). Mordre et al. (2012) have demonstrated poor overall adult outcomes for individuals with both autism and PDD NOS, with high disability rates. Almost all individuals in this study remained unmarried.

The strongest predictors of outcome for the autistic child are IQ at diagnosis and the development of language skills before the age of six (Gillberg and Steffenburg, 1987).

2.12 Dental Problems

2.12.1 Dental Caries

Recent literature has not shown higher levels of dental caries in autistic children compared with the general population. It was shown by Loo et al. (2008), that patients with ASD were 70.5 percent less likely to have a positive caries history than healthy controls. An Israeli study found similar levels of dental caries in non-institutionalised children with ASD and controls (Shapira et al., 1989). However, these findings contrast with those of Jaber (2011) who found a significantly higher decayed, missing or filled teeth score in children with autism compared with age, gender and socioeconomic status matched controls. This study also demonstrated poorer oral hygiene and a lower care index for autistic children. It has been theorised that poor oral hygiene in autistic children may be attributed to the difficulty involved in providing oral hygiene by carers, the child's poor manual dexterity or the detrimental effects of various medications (Jaber, 2011). Klein and Nowak (1999) found a low rate of dental caries in 63% of their study group of 43 patients with ASD, and healthy gingivae in 40% of these individuals. A recent study by Marshall et al. (2010) compared oral health data from 99 children with ASD. They found a high caries history (65%) and rate of novel caries (40%). Caries rate was influenced by ethnicity, with the highest rate of new caries present in children of Asian descent (56%), and the lowest present in children of African American descent (29%), although this was not statistically significant. Caries status in patients with ASD was not related to gender, insurance status or level of parental education, but poor oral hygiene was shown to be the most compelling caries risk indicator. Significantly, this study involved the availability of bitewing radiographs for a high percentage

(63%) of participants, which may explain the diagnosis of higher levels of new caries as compared to the Klein study (Klein and Nowak, 1999). Kopycha-Kedzierawski and Auinger (2008) reported that parents/guardians of children with ASD in the United States of America (USA) were significantly more likely to report the condition of their child's teeth as fair or poor (18%) compared with parents/guardians of non-autistic children (9%). However, the dental problems faced by both groups in the fair or poor group were similar. This research is limited by its telephone survey design, which may have resulted in some selection and reporting bias. Altun et al. (2010a) investigated caries and oral hygiene levels across a broad range of individuals with learning disabilities in Turkey. There was a wide age range in this study (2-26 years). The highest levels of oral hygiene (27%) were recorded in the ASD group, along with a relatively low decayed, missing and filled teeth index of primary and permanent dentitions (dmft/DMFT) of 1.09 and 0.86 respectively. This is in comparison to a dmft/DMFT of 3.7 (5 year olds) and 1.9 (12 year olds) respectively in the general Turkish population (Gokalp et al., 2010). Lowe and Lindemann (1985) reported poorer oral hygiene for children with ASD than controls, and an increased caries rate affecting the primary dentition only. Significantly, recent trends have favoured a decline in caries severity, in children with ASD (Morinushi et al., 2001). Evidence of an increased care index was also included in this study, with a 4% treatment rate of dental caries in 1980, increasing to 58% in 1995. The authors have attributed this reduction to improvements in dental care, oral hygiene regimens, improved dietary intake and more frequent dental visits. However, this research was undertaken in Japan, and is not necessarily generalisable to a UK population. Salivary flow rate, pH and

buffering capacity in autistic children have been shown to be comparable with controls (Bassoukou et al., 2009).

Parents/carers have been shown to become overwhelmingly involved in the dental care of patients with ASD, with between 75% and 88% brushing at least once daily for the patient (Klein and Nowak, 1999; Marshall et al., 2010).

Habits frequently manifested by patients with ASD include food pouching, and this delayed oral clearance may contribute to higher caries rates (Klein and Nowak, 1999). This research has reconfirmed the need to consider patients with ASD at high caries risk (Marshall et al., 2010), and this is reiterated by the American Academy of Paediatric Dentistry (AAPD) who have determined that “persons with special health care needs” are at “increased risk for oral diseases; these diseases further jeopardize the patient’s health” (AAPD, 2008)

2.12.2 Dental Erosion

In addition to dental caries, the dentition should be examined for signs of erosion as autistic children have a tendency to gastro-oesophageal reflux disease with regular regurgitation of stomach contents (Molloy and Manning-Courtney, 2003). Bruxism may also be an issue as it has been shown that 20-25% of autistic children exhibit nocturnal bruxism (Schreck and Mulick, 2000). Muthu and Prathibha (2008) reported a case of severe bruxism in a patient with ASD, necessitating the placement of preformed metal crowns on all primary molar teeth. Another possible solution is the injection of botulinum toxin bilaterally into the masseter muscles, as outlined by Monroy and da Fonseca (2006).

2.12.3 Dental Trauma

A higher prevalence of dental injury has been found in children with ASD compared to the general population, although this difference was not statistically significant (Altun et al., 2010b). Obtaining a dental history may be difficult in autistic children and diagnosis of pathology may be limited to visual examination (Friedlander et al., 2006).

2.12.4 Oral Effects of Systemic Medication

It is important that the paediatric dentist is aware of the possible oral effects of systemic medications, in the child with ASD. Psychotropic medications may have anticholinergic properties, leading to xerostomia and increased caries risk (Brown et al., 2010), and anti-seizure medications can lead to gingival hyperplasia (Seymour and Heasman, 1988). No significant linkage between psychotropic medications and caries risk was proven, however, in studies by both Marshall et al., (2010) and Klein and Nowak (1999). Careful assessment of the autistic patient's medical history is imperative prior to any surgical intervention, as they may be taking drugs, which depress the haematopoietic system. A full blood count and clotting screen will be necessary prior to surgical intervention in this case (Friedlander et al., 2006).

2.13 Barriers to Dental Care

The major problem for autistic patients is not the level of dental disease, but the obstacles surrounding provision of appropriate dental care (Thomas et al., 2007).

2.13.1 Access to Dental Care

Children with ASD may find it extremely difficult to access services and this is influenced by race, area of residence and parental education (Thomas et al., 2007). Marshall et al. (2010) reported that up to 25% of parents experienced difficulty in accessing dental care for their child with ASD. The American Academy of Paediatric Dentistry (AAPD) has stated that patients who have a “dental home” have an increased likelihood of accessing regular and satisfactory dental prevention and restorative care (AAPD, 2008).

The US Surgeon General has highlighted children with special needs as a group who experience difficulty in accessing dental care in the USA (US Department of Health and Human Services, 2000). This acknowledgment was further endorsed by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (DHHS, HRSA, MCHB), in a national survey of children with special health care needs, in 2001. This involved a random-digit-dialled telephone survey of 38,866 families in America. Children with ASD comprised 6.8% of the study population. The service most often lacking in the study population was reported to be dental care (8%), with a reported 78% of participants accessing dental care in the last twelve months (US Department of Health and Human Services, 2001). Similar findings were reported by Lewis et al. (2005) following their assessment of unmet dental care needs among children with special health care needs. They documented that 10.4% of children with a special health care need did not receive all of the dental care they required. This research is limited in its extrapolation to the present study, as there was no attempt to subdivide the study group according to specific healthcare need. It does

however specify that children with increased levels of disability were more likely to suffer unmet dental needs. Nelson et al. (2011), investigated barriers to dental care for children with special health care needs, including children with autism. They reported that one in five children with special healthcare needs has unmet dental care needs, and of this group, 23% of autistic children had unmet dental needs. It was also reported in this study that 9% of parents/carers of patients with ASD considered it difficult to travel to the dentist's surgery, and 15% had experienced difficulties in accessing dental care close to their homes (Nelson et al., 2011).

Mclver (2001) identified five barriers to dental care for children with special health care needs in America, including (1) the primary healthcare system, which may not provide appropriate dental services, (2) parents, who may inadvertently cause decay, or delay seeking dental care, (3) the child, who may not cooperate with dental prevention or interventions or may require complex dental treatment (4) the dentist, who may not treat patients with special healthcare needs, (5) adequate financial remuneration for dental care.

Stein et al. (2011) reported that children with ASD were statistically significantly more likely to object to a toothbrush in the mouth compared to children with other disabilities. In this survey, 50% of parents of children with ASD reported sensory processing problems, which impacted negatively on their child's dental care provision.

Al Agili et al. (2004) undertook a questionnaire survey of 2,057 parents of children with special health care needs in Alabama. Although children with ASD were not included in this survey, it is interesting to note that 35% of parents experienced difficulty in accessing dental care for their children, with 15% stating that their dentist was not willing to treat a child with special needs.

This survey was, however, limited by the low response rate of 21% at first mailing, increasing to 38% at second mailing. The findings are consistent with those investigating barriers to dental care for children with ASD, in that establishing a dental home is seen as a fundamental obstacle to care provision (Thomas et al., 2007; Marshall et al., 2010). Other barriers to dental care reported in this survey included difficulty in securing time off work, low priority of dental care and other reasons such as the child's severe behavioural disturbance (Al Agili et al., 2004). The possibility of extrapolating these findings to patients with ASD has not been addressed in this paper, but anecdotal evidence suggests that barriers to care are similar between the two groups.

2.13.2 Behaviour in the Dental Surgery

Many autistic children have problems cooperating in the dental setting as a result of their communication and social problems. Brickhouse et al. (2009) recently showed that autistic children who exhibit problem behaviour are less likely to have regular dental care. Lowe and Lindemann (1985) confirmed the potential difficulties in examining patients with ASD in their study of 40 autistic patients. The researchers managed to examine only half of the study group at their first attempt.

It is important to be aware of each autistic patient's preferences and past dental experience as they display a wide variation in their ability to cope with dental treatment (Marshall et al., 2008). Children with ASD can experience sensory integration deficits. The autistic child may exhibit disproportionately increased sensory responses (Rogers et al., 2003), and often dislike being touched, but may be reassured by deep pressure (Klein and Nowak, 1998). Children with ASD may become obsessed by light, music or smells. Conversely, they may

also dislike loud noise, bright light or strong smells and therefore become overwhelmed by the dental light, dental motor, or the smells in the surgery (Marshall et al., 2008). Techniques used for behaviour management in autistic patients include – tell-show-do, positive and negative reinforcement, modelling and desensitisation. Visual teaching is an important way of introducing autistic children to dental procedures. The patient may have difficulty in understanding the “tell” and “show” and therefore may reject the “do”. It may be helpful for the patient to practice with a dental mirror, dental film or nosepiece for inhalational sedation at home (Surabian, 2001). Verbal commands should consist of short, clear sentences, such as “look at me”, or “hands down”, with praise contingent on positive behaviour (Klein and Nowak, 1998).

Modelling has been shown to be effective in helping autistic children to accept dental treatment. Marcus and Wilder (2009) compared self-video modelling to peer-video modelling in three autistic children and found increased benefit for self-modelling.

Parents can avoid attending the dentist with autistic children because of the child’s fear of examination and treatment. Many autistic children exhibit fear of the unknown, similar in strength to phobias (Howlin et al., 1973). Desensitisation involves breaking a dental procedure down into individual steps and has been shown to reduce fears and enable autistic children to successfully undergo dental treatment. Luscre and Center (1996) demonstrated that autistic children could be trained to accept a dental examination using a combination of desensitisation, modelling and reinforcement.

One of the most important communication aids for the autistic child is a social story™. This is a short story, written from the patient’s perspective, detailing the entire dental visit. It teaches the child how to behave in each social

situation, and can be read repeatedly by the child and parent prior to the visit (Charles, 2010).

It can be easier for children with ASD to communicate via pictures rather than words and visual pedagogy has been shown to help introduce dentistry for this group of children (Backman and Pilebro, 1999b). The placement of pictures showing how to brush in the bathroom has been shown to improve brushing technique in autistic children (Pilebro and Backman, 2005).

Dental appointments should be short, booked for the same time of day, and the patient should not be kept waiting (Braff and Nealon, 1979).

Financial barriers to dental care may be an issue in some countries, and it is imperative that the paediatric dentist is aware of all available resources for patients with ASD in each region (AAPD, 2008-2009). Low income, and uninsured children were the least likely to access needed dental services, as reported by the 2001 DHHS, HRSA, MCHB survey. This found that one third of these children indicated a health need that was not achieved, sixteen percent of which being dental care. Following a similar trend, 29% of uninsured children reported a need for dental care not obtained (US Department of Health and Human Services, 2001). Comparable data was noted in the more recent survey (US Department of Health and Human Services, 2005-2006). Community organisations may facilitate transportation and assist with financial remuneration (AAPD, 2008) and practitioners should consider this option wherever possible.

2.13.3 Culture and Language

Culture and language may cause barriers to dental care, and there should be facilities available within community services to organise translation services. Advocacy groups may provide cultural support (AAPD, 2008).

It is important to consider the autistic patient in the context of the family as a whole. Parents of autistic children can have their own fears regarding treatment, and occasionally, parents may differ in their attitudes towards the best manner of providing dental care for their child. It is important to fully discuss the options with both parents if possible (Howlin et al., 1973). Parents have been shown to accurately assess their child's ability to cooperate for certain dental procedures (Marshall et al., 2008).

2.13.4 Late Diagnosis

Late diagnosis may represent a barrier to dental care for the patient with ASD. An average delay in diagnosis of 51 months from onset of symptoms has been reported, with the longest delay, of approximately 80 months seen for patients with Asperger's syndrome (Oslejsková et al., 2007). This prevents the instigation of timely behavioural and educational interventions, and anecdotal evidence would suggest a knock-on effect on behaviour in the dental surgery, although the literature does not address this point.

2.13.5 Difficulty in Accessing Specialist Dental Care

Patients with ASD may experience difficulties in receiving specialist referral where necessary. Specialist referral is necessary to confirm a diagnosis of ASD, and to allow the early behavioural intervention that has been shown to

improve developmental outcomes and reduce co-morbidities (Ming et al., 2011). It has been recently reported that many families of patients with ASD did not have a specialist referral through a primary health care provider (Ming et al., 2011). Early referral for preventive dental care is important (De Ocampo and Jacobs, 2006), and it may be that failure of provision of early dental referrals represent a barrier to dental care, although this is not specifically addressed in the literature.

2.13.6 Co-Morbidities

Co-morbidities may compound the barriers to dental care experienced by patients with ASD (Casamassimo et al., 2004). This mail survey of general practitioners in the USA suggested that level of disease represented a barrier to care for almost one third of respondents.

It is not always possible to complete dental treatment for autistic children under local analgesia. Recent research by Loo et al. (2009) showed that patients with a younger age, and additional diagnosis were more likely to show uncooperative behaviour in the dental surgery. Marshall et al. (2007) reported on five predictors of negative behaviour by autistic children in the dental setting, including history of toilet training, tooth brushing and haircutting behaviour, language development and academic achievement. Successful dental treatment of children with autism has been reported using inhalational sedation, although a longer administration than normal was required to achieve sedation (Braff and Nealon, 1979). Pisalchaiyong et al. (2005) demonstrated that both midazolam and diazepam provided effective sedation for autistic patients, in conjunction with inhalational sedation. However, some autistic patients can only be managed safely under general anaesthesia (GA). Recent work by Loo

et al. (2008) showed that 55.2% of patients with ASD were uncooperative and required dental treatment under GA.

Barriers to dental care for children with special health care needs are also perceived by dental care providers. A recent survey of 4,970 general practitioners in the USA reported that as low as 10% of practitioners treated children with special needs on a regular basis (Casamassimo et al., 2004). This may be explained in part by the fact that only 25% of respondents reported hands-on training in this area in dental school. Significantly, 40% of dentists indicated that they would be interested in further training in the area of special needs dentistry. The barriers to dental care described in this survey included, negative patient behaviour, level of disability, level of disease, dentist training, level of training of office staff and funding. This research was limited, however by a low response rate of 24%.

2.13.7 Barriers to Medical Care

Children with ASD also experience barriers to medical care, which may approximate to reported barriers to dental care. Chiri and Warfield (2011) have identified that children with ASD are more likely than those with other emotional, developmental or behavioural problems to report unmet healthcare needs. This paper reports lack of specialist skills as a barrier to medical care, which is in agreement with studies in the dental literature (Casamassimo et al, 2004; McIver, 2001). Similar findings are published by Krauss et al. (2003), who found that over one third of children with ASD had difficulties in accessing medical care during the previous year. Problems cited included problems receiving referrals to the appropriate service and the complication of finding a practitioner with appropriate skills. This is in agreement with findings of Casamassimo et al. (2004), who suggested similar barriers to dental care.

From the literature, diagnostic criteria (American Psychiatric Association, 2000), common characteristics (American Academy of Pediatrics, 2001) and prognostic criteria (Gillberg and Steffenburg, 1987) for the autistic child have been established. That children with ASD experience multiple barriers to dental care is irrefutably documented in the literature (Nelson et al., 2011). However, this evidence is based mostly on data from the USA, and is not necessarily generalisable to a United Kingdom (UK) population. Further to this, medical insurance systems, and their implications in the USA have been cited as core barriers to dental care. This is not anticipated to represent a major barrier to dental care in the UK, due to the system of free dental care for children within the National Health Service (NHS) and salaried dental services. It is also difficult to extrapolate barriers regarding travelling to a dental surgery to the UK, from a country as large and sometimes as remote as the USA. Anecdotal evidence suggests that children with ASD experience considerable difficulty in accessing dental care, for a myriad of reasons. However, as previously stated, there is a paucity of research regarding the barriers to care encountered by autistic children and their parents/carers in the UK. These barriers may involve family or transport problems as well as the patient's inability to accept dental treatment. Parents and carers of autistic children are best placed to comment on these barriers to care.

3.0 Aims

The aims of this research were twofold:

1. To examine the difficulties for children with autism spectrum disorder in accessing dental care in the Hull and East Riding area.
2. If difficulties existed, to develop a strategy to improve this access to dental care for children with autism spectrum disorder.

4.0 Hypothesis

The null hypothesis for the outcome is, “there are no barriers for children with autism spectrum disorder in accessing dental care in the Hull and East Riding area”.

5.0 Study Design

This was a cross-sectional, case control, questionnaire study.

5.1 Primary Investigator

One specialist registrar (SpR) in Paediatric Dentistry (Dr Siobhán Barry) undertook the study. This involved the initial meeting with the autism focus group, questionnaire design, recruitment to the research, analysis and write up of results and implementation of the intervention package.

5.2 Initial Study Population

Initially, the barriers to dental care experienced by children with autism spectrum disorder were assessed, by interviewing a small number of parents/carers of children with ASD in the Hull and East Riding area. These parents were sourced through a local autism focus group in the Hull and East Riding area. The focus group was comprised of six parents/carers. A member of the dental staff in the Highlands dental clinic, who has a child with ASD, and is involved with the group personally, first approached the focus group. A letter of introduction was developed, outlining the aims and objectives of the study, and asking for the input of the group in developing the questionnaire (Appendix 1). Each parent/carer completed the questionnaire. Following this, each question was discussed individually and at length with the focus group. This helped to ascertain the clarity and ease of understanding of the language of each question and its suitability for inclusion in the questionnaire. As a result of this pilot, appropriate alterations to the questionnaire were made. A number of questions were altered to maximise information yield, and the questionnaire

was extended significantly. This meeting provided an approximation of the commonest barriers to dental care encountered by children with ASD in the Hull and East Riding area, from the point of view of their parents/carers. This meeting also provided information regarding the approximate proportions of each barrier to care encountered within the study group. The pilot study informed the main study design.

5.3 Study Group

The study group was comprised of parents/carers of children with ASD in the Hull and East Riding area, who consented to partake in the study, and spoke English. Potential participants were identified from dental records already held by the City Healthcare Partnership (CHCP) Hull community dental services. The primary investigator (SpR Paediatric Dentistry) approached parents/carers of children with ASD who access the dental service when they attended for routine dental appointments. At this time, a full explanation of the research, including the aims, methods and potential outcomes were discussed with each potential study group participant. Every parent/carer approached by the primary investigator agreed to participate in the study. A study group information sheet was provided for each parent/carer who consented to partake in the research, for their records (Appendix 2). This information sheet contained contact details for the primary investigator, and research supervisors, should further information be necessary at a later time. A questionnaire (Appendix 3) and consent form (Appendix 4) was given to each study group participant. In some cases, the parent/carer elected to complete these forms in the dental clinic. Alternatively, some parents/carers decided to take the forms, and complete them at home, and in these cases, a stamped, addressed envelope for

Highland's dental clinic was provided. Study group participants were identified by a unique study number only, so members of the research team could not link any data back to the participants' records.

Parents/carers of children with ASD who did not access community dental services in the Hull and East Riding area were approached by the primary investigator, through a number of special schools in the Hull and East Riding area, including Tweendykes, Ganton, Northcott and St Anne's special schools. The primary investigator approached the Principal teacher in each special school initially. The research aims and objectives, ethical approval, information sheets, consent form and questionnaire were discussed in full. The school Principals in all special schools were enthusiastic about participating in this study. It was agreed that the school Principal would keep a record of the parents/carers who responded, to facilitate a second round distribution of questionnaires. This enabled the study participants from all special schools to remain anonymous. Approximate numbers of children with ASD attending each special school were obtained from the school Principals. Research packs, including questionnaire, and consent form in an A4 sized envelope were supplied, in appropriate numbers to each school, by the primary investigator. Information sheets with contact details for the primary investigator and research supervisors, should additional information be required, were included. These research packs were distributed to parents/carers of children with ASD by the school. Packs were sent, with a covering letter from the school, in each child's schoolbag, with instructions to return completed questionnaire and consent form in the envelope to the school. Study group participants from the special schools were identified by a unique number only, with no patient identifiable

data included, to guarantee anonymity. Only members of the research team had access to the study data.

5.4 Control Group

A comparative control group of parents/carers of healthy subjects were also recruited. This group was chosen from children already accessing the dental services in the Hull and East Riding area for dental care, and was age, gender and socio-economic status matched to the study group. Collecting data on the first half of the research participants' postcodes, and matching with a control patient from an area of similar social status allowed socio-economic status matching.

The primary investigator approached potential control group participants when they attended for a routine dental appointment. Information sheets (Appendix 5) were offered to potential control group participants, and a thorough explanation of the aims and methods of the research was offered to each parent/carer. The information sheet contained contact details for the primary investigator and research supervisors, should further information be required. A questionnaire (Appendix 3) and consent form (Appendix 4) was provided for each control group participant and they were asked to complete it before leaving the clinic. Usually, this did not increase the appointment time for the patient, as the questionnaire was delivered as they arrived at the clinic, and was completed in the waiting room, while waiting for the dental appointment. This was aimed at increasing the response rate from the control group, as they would not expect the same potential benefits from completing the questionnaire and posting it back as the study group participants.

5.5 Inclusion Criteria

The inclusion criteria for this study comprised:

1. Parents/carers of children between the ages of three and sixteen years, with ASD in the Hull and East Riding area who consented to partake in the study and spoke English.
2. Parents/carers of healthy children between the ages of three and sixteen years in the Hull and East Riding area who consented to partake in the study and spoke English.

5.6 Exclusion Criteria

The exclusion criteria for this study comprised:

1. Parents/carers of children under the age of three and over the age of sixteen years.
2. All potential participants who did not speak English.

5.7 Subject Withdrawal Criteria

Participants were free to withdraw from the study at any time without any compromise to their child's current or future treatment. The information received from any research participant who withdrew would have been included in the final analysis, unless specifically requested otherwise by the research participant. However, we did not encounter any withdrawal of research participants during this study.

5.8 Consent

Written, informed consent was sought from all participating parents/carers (Appendix 4). The primary investigator took consent for those study participants attending the community dental services. These patients were identified through records already held by the service, and they were approached on attending for a dental visit. A separate written information sheet for study group (Appendix 2) and control group (Appendix 5) participants was developed. Details of the study, including aims and objectives, methods and possible benefits were explained at the time of obtaining consent. Potential study participants were allowed to read the information sheet when they arrived at the clinic, and if they wished to partake in the study, a consent form and study questionnaire was provided, along with a self-addressed envelope for the dental clinic. All potential study group participants approached in this way were made aware that participation in the study was discretionary, and they were free to withdraw consent at any time, without negatively affecting current or future dental care. They were allowed two weeks to complete and return the consent form and questionnaire.

A consent form and questionnaire was included with the information sheet, for those potential study participants who were contacted through the special schools. Information details for the primary investigator were supplied should the potential study participants have required any further information or clarification. The participants were made aware that it was not mandatory to take part in the study and that they were free to withdraw from the study at any time, without compromise to their existing or future dental treatment. They were allowed two weeks to complete and return the questionnaire to the school Principals.

There was a facility for anybody who could not read or adequately understand the information sheet/consent form to discuss it with the primary investigator.

A second round of information sheets, consent forms and study questionnaires were distributed after two weeks. These were posted to those potential study group participants approached through the dental services, and by the school Principal, for those potential study group participants approached through special schools.

If a research participant who had given informed consent lost capacity to consent during the study, the participant would have been withdrawn from the study. Data already collected would have been used in the study, but no further data would have been collected.

5.9 Storage of Participants' Personal Data

All research data was stored in a locked filing cabinet, behind the reception area in Highlands' dental clinic. This area was not accessible to the public. Access to this filing cabinet was be restricted to the primary investigator and supervising Consultant in Paediatric Dentistry.

5.10 Patient Identifiable Data

No patient identifiable data was held for the purposes of this research. Personal data was anonymised and all research participants were identified by unique identification number only. This ensured confidentiality of patients' personal data. All personal and research data will be stored for a maximum of one year following completion of the research. All research data will be confidentially destroyed by shredding at this time.

5.11 Questionnaire

A questionnaire was developed regarding potential barriers to dental care for patients with ASD in the Hull and East Riding area. An alternative approach would have been to use qualitative interviews with research participants (Harris and Brown, 2010). The questionnaire approach has been shown to provide information regarding large populations, whereas qualitative interviews can gather more in-depth information (Harris and Brown, 2010). The use of a questionnaire approach was chosen for this study, as it was felt that the necessary information could be easily ascertained from questionnaires. In addition undertaking qualitative interviews with 112 parent/carers would have been prohibitively time-consuming.

Reliability is defined as the extent to which a measure is stable and produces similar results (Sushil and Verma, 2010). Test-retest reliability involves administering the questionnaire to the same individuals on two different occasions, and is a method of assessing its reliability. The questionnaire was not re-tested in this study, as it would have been onerous for parents/guardians to devote additional time to the completion of the questionnaire on a second occasion. This questionnaire was initially piloted, using an autism support group, in the Hull and East Riding area. Further to this pilot, the questionnaire was expanded and adjusted, with considerable input from an autism focus group. Parents/carers described the potential difficulties in travelling to the dental surgery by car, versus by public transport, and questions regarding both transport methods were included in the questionnaire. Parking close to the door was identified as a potential benefit by parents/carers and similarly this question was included. A number of potential trigger factors for negative behaviour within the dental surgery were described by parents/carers, including strange tastes and enclosed spaces. These potential trigger factors were added to the questionnaire. Additionally, a number of predicted negative behaviours were listed by parents/carers, including spitting and head butting. These predicted behaviours were included in the questionnaire. Parents/carers described a number of behaviour management techniques which may potentially be used by parents/carers of children with ASD, including the use of Makaton™ and Picture Exchange Communication System (PECS). This allowed the inclusion of a specific question regarding the behaviour management techniques, which were utilised by parents/carers in the questionnaire. The questionnaire allowed the research team to achieve a better understanding of the potential barriers to dental care experienced by these

patients. It consisted of mostly closed-ended questions, with space for further comment by patients/carers regarding individual barriers to dental care encountered by their children (Appendix 3).

The primary investigator offered the information sheet to potential research participants when they arrived at the clinic, with a comprehensive explanation of the research aims, objectives and possible outcomes. Questionnaire and consent form were supplied to all parents/carers who agreed to participate in the study.

The study group information sheet, consent form and questionnaires were distributed to parents/carers of children with ASD through the Principals of special schools in the Hull and East Riding area.

The information sheet and consent form took approximately 15 minutes to read and sign. The questionnaire took approximately 30 minutes to complete.

Reading and completion of the information sheet may have slightly prolonged the appointment time, for those attending the dental clinic, but anecdotally, this did not present a problem, as most individuals in both study and control groups completed the forms while waiting for the dental appointment.

5.12 Statistics

Numerous meetings took place with the statistician, to discuss the research project and appropriate methods of statistical analysis. It was decided that the focus group meeting needed to take place initially, in order to establish approximate proportions of each barrier to care within the study group. This information allowed the study to be powered. A further meeting took place to discuss the power of the study, and the statistical methods, which were used to analyse the data. The primary outcome measures were barriers to care for

patients with autism spectrum disorder in the Hull and East Riding area. The sample size consisted of 56 parents/carers of children with ASD in the study group, and 56 parents/carers of healthy children in the control group. Participants were not randomly allocated. Sample size was calculated using software for determining sample size called PS Power and Sample Size Program. The study matched cases and controls with 1 matched case per control. This meant that the samples were not independent. Estimates from the pilot study showed a probability in cases of 50% and in control 80%. The correlation coefficient for matched cases and controls is not known but some authors state that it is better to use a small arbitrary value for r , say 0.2, than it is to assume independence (a value of 0) (Dupont, 1988). In this study a correlation coefficient of 0.2 was used. Aiming to detect a true odds ratio of 0.25 based on the probabilities stated above, the study needed 51 case patients and 51 control patients to be able to reject the null hypothesis that this odds ratio equals 1 with power 80% and 5% significance level. Adding a further 10% in each group, to allow for dropouts, the study group and control group would each require 56 study participants. Following ethical approval, a further meeting was arranged with the statistician, for database design. When data collection was completed, categorical data was summarized using proportions. Cases and controls were compared using Chi-Square and Fisher's Exact tests where appropriate. Fisher's Exact test was utilised when at least one of the cell values was less than 5. Significance was deemed at $p < 0.05$. 95% confidence intervals were computed. Ordinal data was presented using medians and 25th and 75th centiles. Ordinal data was compared using Mann Whitney U test. All data analysis was carried out at Leeds Dental Institute, University of Leeds.

5.13 Indemnity

The University of Leeds provided indemnity for this research.

5.14 Monitoring and Audit of Research

This research underwent regular monitoring and audit. Meetings were held with research supervisor on a monthly basis or more frequently if needed.

5.15 Ethics Application

Ethical approval was necessary for this research. There are several ethical issues involved in contacting parents of children with ASD. There may have been a misconception that parents were being targeted because they had a child with ASD. This was overcome by obtaining consent and providing an information sheet, outlining the reasons for the study prior to sending out any questionnaires. Parents had the option of declining to participate in the study, without compromise to their child's current or future dental care.

The questionnaire may have enhanced fears that there are barriers to dental care for children with ASD. This was overcome by explaining the aims of the study in the introduction letter. This letter reassured parents that we hoped to find ways to overcome any barriers to dental care experienced by patients with ASD.

This questionnaire may have potentially excluded parents of children with ASD who are illiterate. If anybody had a problem in completing the questionnaire, the primary investigator helped to complete it on a one to one basis with him or her. Care was taken not to influence the answers to the questions by prompting.

The questionnaire may have been upsetting for parents/carers of patients with ASD, if they recalled previously traumatic dental experiences. We attempted to overcome this by explaining carefully the proposed outcomes of the research in the information leaflet.

5.15.1 Dental Research Ethics Committee (DREC)

An ethics application was submitted to DREC on November 2010. This was subsequently returned for further clarification of a number of minor issues. It was suggested that, as the autism focus group was not recruited through the NHS, that a meeting with this group could go ahead, in order to pilot and extend the questionnaire. Following this pilot study, the ethical application was resubmitted to DREC, and subsequently approved.

Following ethical approval by DREC, it was submitted to the University of Leeds, for sponsorship review. This was approved, pending a small number of minor adjustments, on 17/03/2011 (Appendix 6).

5.15.2 National Research Ethics Service (NRES)

The ethical application was then submitted to NRES, in order to obtain the necessary ethical approval to commence the study. This submission was via an Integrated Research Application System (IRAS) form, and was found to be suitable for proportionate review.

Ethical review was undertaken by the Proportionate Review Sub-Committee of the NRES Committee North East – Newcastle and North Tyneside 2 Research Ethics Committee, on 27/05/2011. They considered the application to be well written and the sensitivities regarding the initial approach and consent

recognised and dealt with appropriately. The sub-committee had, however raised two points regarding the research on 23/05/2011. These points were answered via e-mail, and read as follows:

1. It was recognised that parents/carers of children with ASD might become upset or distressed while reading and completing the questionnaire, as the idea that there are barriers to dental care for children with ASD is reawakened. This had been dealt with in the information sheet, by explaining the possible beneficial outcomes of the research for children with ASD in the Hull and East Riding area. Despite this explanation, some study participants may remain distressed, following recollection of a previous, traumatic dental visit, and might want to discuss this. Clarification was required by the sub-committee of the strategies in place to deal with this scenario.

It was explained to the sub-committee that all parents/carers involved in the study would have access to the paediatric dental team, who would be able to help them with any difficulties they might have, and refer them to the relevant service for advice and help. There is also a parent support group in the Hull and East Riding area, which could have been contacted by the researchers, to help with any issues. There was also access to the psychology department in Leeds General Infirmary for advice and help. In addition to this, parents/carers could have been directed to the patient advice and liaison service (PALS) if necessary.

2. Non-English speakers were excluded from this research, and the use of interpreters ruled out due to cost implications. The sub-committee questioned if the non-English speaking population was a significant

group, in the Hull and East Riding area, and whether this group would experience distinct barriers to accessing dental care. It was also queried how this would be dealt with, when writing up the results.

It was explained to the sub-committee that there were likely to be few, if any non-English speaking people in the Hull and East Riding area and a high number of non-English speaking participants was not expected. Therefore, their exclusion would not be expected to bias the results. Further to this, it was explained that the inclusion of non-English speaking study participants might have introduced a confounder to the study. Non-English speaking individuals may have experienced barriers to dental care, which are not related to the research question. This issue would be fully explored in the research write up.

On behalf of the committee, the sub-committee gave a favourable ethical opinion of the research on 27/05/2011. This decision was subject to management permission being obtained from the National Health Service Regional and Development (NHS/HSC R&D) office prior to the commencement of the research (Appendix 7).

An annual progress report was sent to the Proportionate Review Sub-Committee of the NRES Committee North East – Newcastle and North Tyneside 2 Research Ethics Committee, on 17/06/2012. Receipt of this report was acknowledged by letter (Appendix 8).

5.15.3 Research and Development (R&D)

Contact was made with the local R&D office in the Hull and East Riding area, which was based in Castle Hill hospital. The R&D form generated by IRAS and including sponsorship confirmation was submitted, along with the site specific

information form (SSI) for CHCP Hull and all the supporting documentation. However, it transpired that this R&D office did not deal with the CHCP Hull organisation. The chief executive of the CHCP Hull, Mr Andrew Burnell was contacted directly, and began to make provisions for the York R&D office to manage R&D applications from the CHCP Hull. At the time, CHCP Hull was a very new organisation, and had not yet made provision for the R&D process. However, this process was due to continue for a number of months before finalisation of terms, and the York office would not have been in a position to deal with the R&D for this research for quite some time. This would have resulted in an unacceptable delay for this research, and, taking this into account, the R&D form, SSI form and supporting documentation were submitted directly to Mr Andrew Burnell, who was able to make an executive decision to grant R&D approval for the study on 03/06/2011 (Appendix 9).

5.16 Potential Benefits for the Study Group

Patients with ASD and their parents/carers in the Hull and East Riding area will potentially benefit from this study. It is hoped that the intervention developed, in the form of a pre-appointment questionnaire, specifically enquiring about the child's individual preferences during dental treatment will help to overcome barriers to dental care in the Hull and East Riding area. The development of pre-appointment photographs of the dental clinic and staff, and a social story™ should help to familiarise children with the dental experience. The dental application, developed for smart phones and tablet devices will allow patients to take a virtual tour of the dental clinic, prior to arrival, familiarise themselves with dental staff, and experience the sights and sounds of the dental surgery.

5.17 Potential Benefits for the Control Group

There are no benefits for control group participants.

5.18 Potential Risks and Burdens for Study and Control Group

Participants

As previously stated, reading and completing the information sheet, consent form, questionnaire and feedback form slightly increased the patient's appointment time.

There was the potential for parents/carers of children with ASD to become upset while reading the questionnaire, as it may have provoked fears that barriers to dental care existed for their children. This potential risk was acknowledged during application for ethical approval for the research, and was addressed by providing an information leaflet for the parents/carers. This leaflet explained the possible benefits of this research for children with ASD. Despite this explanation, there was the potential for some parents/carers to become distressed. There were numerous services available to support these parents/carers, including the parents support group in the Hull and East Riding area, the psychology department at Leeds General Infirmary, and PALS. There was a protocol in place, for the research team to refer these parents/carers to the relevant service for advice.

6.0 Results

6.1 Pilot Study

The pilot study was undertaken in January 2011. Initially, a questionnaire was developed. This included questions regarding potential barriers to dental care for children with ASD in the Hull and East Riding area, which were noticed anecdotally in the dental clinic. The chief investigator travelled to Hull, to attend a focus group of parents/carers of children with ASD. A dentist colleague from the CHCP Hull, who is also the mother of a child with ASD, and a member of the focus group, initially contacted this group. The group included another five parents/carers, resulting in a group of six participants.

Initially, each participant completed the questionnaire. Following this, each question was given thorough consideration regarding its relevance and clarity. The questionnaire was considerably expanded, with the addition of further questions regarding barriers to dental care experienced personally by children of the focus group participants.

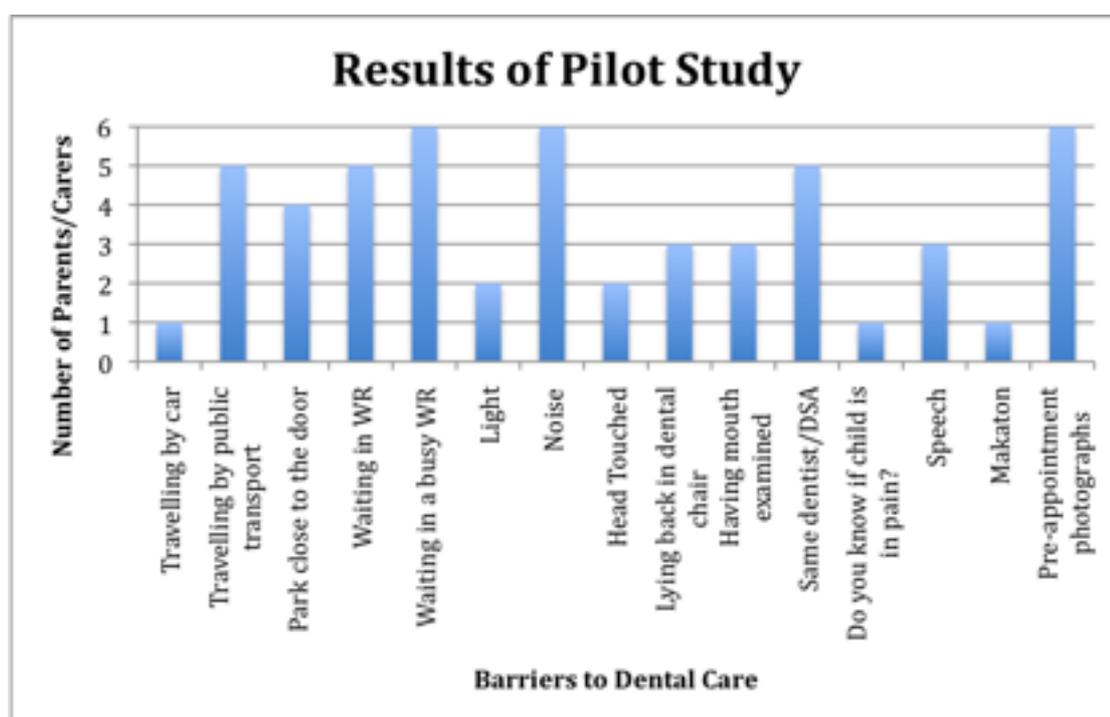


Fig 1. Results of Pilot Study

Results of the pilot study demonstrated numerous potential barriers to dental care experienced by children with ASD in the Hull and East Riding area (Fig 1). One of the most common barriers to dental care reported was waiting in a busy dental waiting room, which was considered universally problematic by study participants. Parents/carers reported more difficulty in waiting in a busy waiting room ($n=6$), than a less busy one ($n=5$). A large number of parents/carers ($n=5$) reported difficulty in travelling by public transport, while a far lower number of those who travelled by car experienced problems ($n=1$). Parking at the dental surgery emerged as a potential problem for parents/carers, with 4 parents/carers reporting difficulty in finding a space close enough to the door of the practice.

When investigating potential barriers to dental care in the dental surgery, loud noise was universally reported as problematic ($n=6$), for example the dental drill.

Bright light, and head touching was found to represent a problem for 2 participants' children. The routine of seeing the same dentist and dental nurse was reported to be helpful, by 5 participants.

A significant barrier to dental care was the identification of dental pain, in patients with ASD, with only 1 respondent reporting confidence in his/her child's ability to communicate dental pain.

Communicating with dental staff emerged as a significant barrier to dental care, as only 3 parents/carers surveyed reported that their children communicated through speech. Further to this, 1 participant reported that his/her child used Makaton™ (a system which uses signs and symbols to assist communication) as a communication aid.

Interestingly, we saw universal recommendation (n=6) for the inclusion of pre-appointment photographs of the dental staff and clinic, with the initial appointment.

6.2 Results of main study

The study involved 112 participants. This included all 92 parents/guardians who were approached in the community dental services and 20 out of 50 parents/guardians who were approached via special schools. The parents or legal guardians of 56 children with ASD completed the study in addition to the parents or legal guardians of 56 healthy control subjects without ASD. Study and control groups were gender, age and socio-economic status matched. In this study, residential area was used, in an attempt to normalise for socio-economic status. Mean age was 9.82 (\pm 3.27) years in the study group and 9.75 years (\pm 3.38) in the control group with no significant difference between the two groups. Participant children were mostly male (43 children in each

group) with 13 females in each group. There was a broad range of perceived severity of ASD within the study group, with 11 parents/carers classifying their child as mildly affected, 13 reported their child to be moderately affected and 26 parents/carers described their child as severely affected. Six participant children had a diagnosis of Asperger's syndrome (Table 1).

6.2.1 Attendance at Dental Services

There was no significant difference in attendance at dental services amongst the two groups although numerically more subjects without ASD attended a dentist (55 versus 50, Fisher's Exact Test p value = 0.113)(Figure 2). Reasons for not attending dental services by the study group participants were outlined as;

1. *"He has special needs"*
2. *"We attended a dental access centre with a special needs dentist, who worked with our child, seeing him every three months, to help to gain his confidence. He finally sat on the dental chair and allowed a dental examination. Unfortunately, this dentist left and wasn't replaced. We took our child to another dentist, but as he doesn't like change, he kicks off any time and hasn't had a thorough examination."*
3. *"Our child was seen regularly by the consultant paediatric dentist in Hull, but has not had an appointment for approximately two years. I think we must have missed an appointment and not been reappointed. The only number I had for the service was a mobile number that was no longer in service."*
4. *"It's hard to find an NHS dentist"*

5. *“There was a mobile dentist at her school but it has stopped now and my dentist won’t take her as she has autism. He said that she needs to see a specialist.”*
6. *“I don’t believe she would sit on the chair”*
7. *“He has attended dental services, but now it’s a bit difficult as he is in a different school, as his dentist does not open on a Saturday”*
8. *“We were not aware of any specialist dentists. Also, we have not expected him to be able to sit for any great length of time”*
9. *“We have taken him to an NHS dentist in the past but he became too stressed. He bit the dentist.”*

One parent/carer in the control group indicated that they had difficulty in accessing dental care for their child. They felt that their dentist was unable to offer appointments during the school holidays.

There was a significant difference between the two groups regarding difficulty experienced in attending dental services (Figure 3). In the group with a diagnosis of ASD 36% reported that they had experienced difficulty accessing dental services versus 5.5% in the control group (Fisher’s Exact Test, p value < 0.001). The major difficulties outlined were;

1. *“My child doesn’t respond to any questions or requests and he is afraid of any doctors”*
2. *“The time spent in the surgery is not enough to make my son feel at ease, as the next person’s waiting”*
3. *“We were referred by his paediatrician one month ago, but his father (a GP) had to push for this appointment, which is a cancellation”*
4. *“Only the fact that he finds waiting extremely difficult”*

5. *“He was initially reviewed locally by a non-specialist, which was challenging and of limited benefit. This has improved dramatically since we were referred to a specialist service”*
6. *“The dentist had no patience for my son, and got annoyed”*
7. *“My son visited the dentist but when we wanted him to go again, we had difficulty getting another appointment. I think he should have regular checks like any other child”*
8. *“We rang early this morning to confirm appointment”*
9. *“The lack of NHS dentists and his inability to deal with new situations”*
10. *“Not enough patience with him”*
11. *“Not accepting patients on the NHS”*
12. *“Waiting at the dentist”*
13. *“Refusing to let the dentist look at his mouth”*
14. *“Kicking out at the dentist”*
15. *“Screaming at being held then starts head-butting”*
16. *“We had to be referred by the school nurse and there was a significant period of time when we had no dentist”*
17. *“He is not that good waiting and the dentist always seems to be running late. By the time he gets to see the dentist we are both fed up”*
18. *“Most dentists have no real special needs training. Too much waiting for appointments – it can take months. Too long a wait for treatment. Increased oral sensitivity and therefore heightened reluctance to cooperate in the clinic”*
19. *“There was a specialist based service but due to cut backs, we’re now seen at a community dental service”*

20. *“Problems getting the child to leave the house for various reasons, i.e. lack of social skills”*

21. *“He needs to attend a dentist who understands autism and can continue seeing him in the same place each time. Even if the dentist has to change, as long as the premise is the same, it wouldn’t be much of a problem”*

22. *“He becomes nervous, and his original dentist doesn’t seem to know how to handle this”*

23. *“We didn’t know the service was available until recently”*

24. *“We would like to attend more often”*

Only three parents/carers in the control group commented on difficulties experienced in accessing the dental service. One described travelling for one hour by bus to the main station, and then for forty-five minutes from the station to the dental clinic, with a similar return journey. Another parent/carer felt that her son had a problem with trust, and was worried about needles. He was nervous just sitting on the dental chair. The third parent/carer felt that they had no severe difficulties in accessing dental care for their child, but appointments were not freely available.

6.2.2 Transport to Dental Services

Transport to the dentist proved more difficult for those respondents whose children had a diagnosis of ASD, whether this transport was by public or private means (Table 2; Figure 4; Figure 5). A significant difference was also observed when examining whether parking close to the door of the dental surgery was relevant, with 41% of respondents in the ASD group noting it to be important. Nobody in the control group considered that parking close to the door of the

dental surgery would be beneficial (Fisher's Exact Test, p value < 0.001)(Figure 6).

In the study group, three parents reported that they did not have a car. Another felt that their child would experience difficulty in travelling to the dental clinic by car if she didn't know where she was going, or if it was a long distance. Three parents/carers commented that their child was reluctant to take the bus. One of these children was anxious about the number of people on board, another just didn't like the bus and the third child suffered from motion sickness.

Within the control group, one parent/carer reported that their child gets "fed up and uptight", when travelling to the dental surgery, due to the distance travelled.

6.2.3 Inside the Dental Surgery

Waiting in the waiting room was deemed to be difficult in a higher percentage of respondents in the study group (64.3%) versus the control group (3.6%) (Fisher's Exact Test, p value < 0.001)(Figure 7). If the waiting room was busy, this effect was increased; 83.9% cases versus 5.4% controls (Fisher's Exact Test, p value < 0.001)(Figure 8). Within the group of cases who initially reported no difficulty in waiting in the waiting room 12 out of 20 expressed that there would be a difference if the waiting room were busy. Additionally 35 out of 36 of the respondents in the study group who initially felt they would experience difficulty in waiting, felt that it would make an additional difference if the waiting room were busy. One parent/carer commented that her child's difficulty in waiting varied according to his mood on the day. Four parents/carers felt that waiting would only be a problem if the wait was prolonged, one quoting ten minutes as the maximum acceptable waiting time. One parent/carer felt their child would become very anxious in a waiting room.

One parent/carer commented that a small waiting room would exacerbate the problem and another felt that their child would need to wear earmuffs in a busy waiting room.

6.2.4 Strategies for Accessing the Dental Surgery

A significantly greater proportion of subjects in the study group felt that phoning the dental clinic prior to their arrival to permit immediate access to the dental clinic would be helpful 71.4% versus 8.9% (Fisher's Exact Test, p value < 0.001)(Figure 9).

6.2.5 Appointment Time

Respondents were asked to rate their preferred time for a dental appointment from 1 to 5 with 1 signifying the most favourable appointment time. Medians are reported for each of the pre-specified appointment times with first appointment deemed to be the most favourable appointment overall (Table 3; Figures 10 A-E). Differences between preferred times was conducted using Mann Whitney U test. The sole significant difference between groups was a preference for an appointment immediately post lunch in the study group (p=0.047).

6.2.6 Behaviour of Children

Eighty-nine point three percent of study group respondents expressed that their child's behaviour was liable to suddenly change versus 10.3% in the control group (Chi- Square, p value <0.001). All respondents to this question in the study group considered loud noise to be a likely trigger for behaviour change.

The other most commonly cited triggers in the study group were strange taste, strange smell, head touching, bright lights and enclosed spaces (46, 46, 44, 44 and 43 out of 50 respondents respectively).

There were significant differences noted in the type of behaviour, which was predicted to be displayed by the children. In the control group, all respondents who anticipated a change in behaviour suggested that they would expect the child to cry, with no other expected behaviours noted. In contrast, in the study group, a range of behaviours was expected. The most commonly cited behaviours were crying (n=39), hitting/lashing out (n=37) and laying on the floor (n=29). Self-harming was predicted by 25 parents/carers, and 20 study group children were expected to head but. Sixteen children were predicted to bite dental staff/their parents, and spitting was anticipated by 10 parents/carers. Nine children in the study group were predicted to display positive behaviour (Table 4).

In addition to the possible behaviours listed in the questionnaire, the parents/carers in the study group anticipated a number of additional behaviours, including;

1. *“Screaming/shouting loudly”*
2. *“Talking in a funny voice”*
3. *“Screaming and trying to get away”*
4. *“Biting his own hand”*
5. *“Being flustered and confused”*

Significantly more subjects with children with a diagnosis of ASD utilised specific behaviour management techniques with their children (66.1% versus 10.7%) (Chi- Square, p value < 0.001).

The behaviour management techniques utilised included;

1. *"Talking to him"*
2. *"Being close to him"*
3. *"Allowing him to look in a mirror, so that he can pull faces"*
4. *"Stop signals"*
5. *"Traffic signs"*
6. *"Give basic, easy instructions"*
7. *"Praise him when he responds appropriately"*
8. *"Talking in a calm, reassuring manner at first, then sternly if he is still not co-operating"*
9. *"Calm, slow talking and explaining what's happening and why, in simple one word or two word phrases"*
10. *"Stroking the palm of his hand in a circle"*
11. *"Massaging his forehead"*
12. *"Applied behaviour analysis (ABA) – this technique uses counting and waiting/stop signals at set times from five minutes to one minute. Good behaviour is rewarded with reinforcers such as books/DVDs/cards/sweets"*
13. *"The use of key words, known to the child"*
14. *"The use of a quiet area"*
15. *"Distraction, such as food"*
16. *"Stroking arms"*
17. *"Use of picture exchange communication system (PECS) before going to the dentist"*
18. *"Talking softly"*
19. *"Removing him from what is upsetting him"*
20. *"Picture cards"*

21. *“Asking the child to breathe deeply”*
22. *“Restraining the child by holding”*
23. *“Asking the child to stop the negative behaviour”*
24. *“Songs and repetitive games”*
25. *“Bringing books that the child is familiar with to read in the waiting room”*
26. *“Tickling”*
27. *“The use of social stories”*
28. *“Signing the Makaton for “calm down”*
29. *“The promise of McDonalds afterwards”*
30. *“The use of visual charts”*
31. *“Positive happy language”*
32. *“Taking a favourite toy to the dental appointment”*

6.2.7 The Dental Surgery

Significant differences between the two groups were noted when examining what the child was happy to allow within the dental surgery. Consistently, children with ASD were suggested to be less happy to have dental procedures performed. Fifty-nine percent of study group respondents felt their child would be happy to wear protective glasses versus 94.6% in the control group (Fisher's Exact Test, p value <0.001). Similarly, 57% of children with ASD versus 91% of children without were expected to be happy to lie back in the dental chair (Fisher's Exact Test, p value <0.001). Children with ASD were believed to be less likely to be happy to have their mouth examined or accept air/water in their mouths (57% versus 84%, Chi-Square, p = 0.002; 34% versus 82%, p < 0.001 respectively)(Table 5).

There was no difference in the proportions of subjects who would respond positively to being shown dental equipment beforehand or being seen by the same dental team at each visit (73% versus 84%, Chi-square, $p = 0.167$; 95% versus 89%, Fisher's Exact Test, $p = 0.489$ respectively).

6.2.8 Dental Pain and Communication

Significantly fewer respondents in the study group were able to recognise if their child had dental pain (68% versus 98%, Fisher's Exact Test, $p < 0.001$). In order to examine this further, methods of communication used by respondents were assessed. Speech was the method of communication utilised in 68% of the study group whereas it was the sole method of communication in the control group (Fisher's Exact Test, p value < 0.001). Methods of communication utilised in the study group are outlined in Table 6. These included the use of Makaton™ (14.3%), and the utilisation of a picture exchange communication system (PECS)(19.6%). It was noted by 10.7% of parents/carers that their children did not communicate. The "other" category (34.7%) included communication via body language, sign language, show and tell, pointing, guiding, eye contact, screaming, nodding, lashing out, inducing vomiting, key words, making silly noises and gestures. One parent/carer reported the use of a timetable and calendar, to explain timeframes and give an outline of each day's activities.

6.2.9 Strategies for Improving Dental Attendance

Potential strategies for improving dental attendance and compliance were next examined. All suggested strategies were deemed to be significantly more

helpful amongst the group with children with a diagnosis of ASD (Table 7).

These included;

1. The inclusion of some photographs of the dental clinic and staff, for the child to see before his/her dental visit (Chi-Square, $p < 0.001$)
2. The inclusion of a social story™ about the dental visit with the child's initial appointment (Chi-Square, $p < 0.001$)
3. The inclusion of a symbol strip about the dental visit with the child's initial appointment (Chi-Square, $p < 0.001$)
4. Allowing the parent/carer to take a photograph of the child in the dental waiting room or on the dental chair (Fisher's Exact Test, $p < 0.001$)
5. The dentist to sign, "finished" in Makaton™ when treatment is complete (Fisher's Exact Test, $p < 0.001$)

Additionally, more subjects in the study group would find it helpful if a domiciliary dental visit was arranged should their child refuse to attend the dentist (19/25 versus 4/25, Fisher's Exact Test, $p = 0.001$).

6.3 Frequency of Dental Visitation

Respondents' views were assessed, regarding the frequency with which they would expect their child to require a dental visit after an initial relationship was established. Significant differences were noted between the two groups regarding the frequency of review appointments thought to be necessary (Table 8). A significantly higher number in the study group preferred 3 monthly appointments (Chi-Square, $p < 0.001$) and a significantly higher number in the control group preferred 6 monthly (Chi-Square, $p < 0.001$) dental appointments. A higher number of parents/carers in the control group requested monthly appointments (3 versus 2), although this was not significant. Equal numbers of

parents/carers in the study and control groups indicated that 2 monthly appointments would be appropriate for their children (n=1 in each group, p= 1.000). Three parents/carers utilised the “other” section on the questionnaire, related to this question. Two parents/carers in the study group requested an alternative appointment schedule for their children, selecting 4 monthly and yearly appointments as the ideal recall intervals for their children. One parent/carer in the control group suggested an alternative appointment schedule, selecting a 4 monthly recall interval as appropriate. The difference between study and control groups for the “other” category was not significant (Fisher’s Exact Test, p= 1.000).

6.3.1 Any other thoughts or ideas about difficulties your child may experience while visiting the dentist?

Parents/carers were questioned regarding any other thoughts or ideas that they may have regarding possible barriers to dental care for their children, or mechanisms to help overcome these difficulties. Parents/carers described the Applied Behaviour Analysis (ABA) programme that some patients with ASD were accessing through therapy centres. This had broken the dental visit down into a number of manageable steps for the patients. It was suggested that schools should use this process, to prepare children with ASD for the dental visit. They also suggested that we allow parents to visit the dental surgery prior to their child’s dental visit, to familiarise themselves with the layout and any possible distractions, possibly by organising an open day. It was also advised that a message be sent by text, if the dentist was running late, or that we organise a quiet room for children with ASD to wait in. It was felt that some

children with ASD may prefer to wait in the car, and therefore it would be helpful if a member of staff could come to alert them when the dentist was ready. Parents/carers felt that appointments for the last session of the afternoon allowed patients to leave school early, which would improve their cooperation in the dental surgery, as attending the dentist was seen as preferable to being at school.

A number of parents/carers felt that their child would not cope with dental treatment under local anaesthesia or intravenous sedation, due to needle phobia. Some patients would therefore require a general anaesthesia for any necessary dental treatment.

Parents/carers indicated that their children might need to talk through their nerves with the dental team prior to any treatment, in order to help them to relax. It was also suggested that minimal use of language would be beneficial, with the emphasis being placed instead on visual preparation for the dental visit. A game involving allowing the child to go “up and down on the chair” and to “spin on a spinning chair” was suggested. It was also recommended that a number of visits without dental treatment would be desirable, to acclimatise the patient with the dental setting. It was recommended that two or more children from the same school or class attend the dental clinic together to give the visit a “school trip” feeling.

It has been advised that the dentist greets the patient without wearing a mask or gloves in the first instance. The parents/carers also advised that the dentist should avoid questions such as “would you like to sit on the chair?” as the patient may feel that they have a choice. They should instead use direct commands such as “sit in the chair”. Parents/carers recommended the provision of visual aids such as books or videos in the dental waiting room,

showing the steps involved in the dental visit. This would help to familiarise the patient with the dental setting, prior to entering the dental surgery.

It was suggested by one parent/carer that there were too many distractions in the dental surgery and that we should remove anything that children may want to play with. This parent/carer also recommended that we introduce some colour in the dental surgery or sensor lights on the ceiling for the patient to look at during the dental examination. The use of cartoon posters on the ceiling was also advised.

Parents/carers noted the lack of “special needs” knowledge, understanding and training amongst general dental practitioners (GDPs), but felt that accessing specialist services resulted in infrequent appointments, which contributed to the patient’s dental anxiety.

Some parents indicated that they needed a second person to accompany them to the dental visit, to help with holding the child. Face to face contact between parent and child was advocated as a relaxation technique for the child. Some parents/carers recommended a general anaesthetic as the safest method of achieving dental care for the child with ASD.

It has been identified by parents/carers in this study that emergency appointments should be timely for children with ASD as they demonstrate a poor tolerance of dental pain. Familiarity with the same dentist and dental nurse was specified as being important for the child with ASD and frequency of dental visits would improve acceptance of the dental visit. Time off work for parent/carers to attend the dental clinic with children was noted to be a difficulty.

Parents/carers reported a difficulty in getting patients into the dental clinic, and feel they have to explain that their child has ASD at each visit. It has been

recommended that staff ask simple questions only. It was also noted by parents/carers that children with ASD might become upset by the sounds and/or smells of the dental environment, which is exacerbated by seeing previous patients leaving the surgery.

A pre-appointment social story with PECS pictures was highly recommended.

It was suggested by parents/carers that a specialist dental service closer to home would be beneficial for the patient with ASD, particularly for those with transportation difficulties.

Travelling to undergo comprehensive dental care under GA was described as “a mothers worst nightmare” and longevity of dental appointment was seen as an important factor, with increased length of treatment associated with greater difficulties for the child with ASD. The sounds within the dental surgery have also been identified as problematic, in particular the noise made by the dental suction. One patient was concerned about possibly swallowing any dental equipment that may be dropped in his mouth. Parents/carers felt that children with ASD respond very well to “tell, show, do” although they may not fully understand the explanations given. Parents/carers have raised concern that patients may be in a school some distance from home, necessitating dental appointments during school holidays only. This has resulted in difficulties in organising appointments.

Patients with ASD may speak differently from other children, and parents/carers have noted that other parents/children in the waiting room notice this and might look at the child. This would increase the child’s anxiety and possibly reduce cooperative behaviour.

Within the control group, parents/carers asked that the patient be addressed directly by dental staff rather than through the parent, and that all procedures be fully explained to the patient.

Some parents/carers commented that their children were frightened by the thought of needles and dental extractions. These children were predicted to be reluctant to allow a mouth examination. Other parents/carers commented that their children were very happy to attend the dentist.

	Cases	Controls
Diagnosis of ASD	56	56
Age (years)*	9.82 ± 3.27	9.75 ± 3.38
Male: Female	43:13	43:13
Diagnosis of ASD	56	0
Mild	11	
Moderate	13	
Severe	26	
Asperger's Syndrome	6	
Attends Dental Services	50	56

Table 1 Basic demographics of study participants. * Mean ± standard deviation.

	Study group n = 56	Controls n = 56	p value
Difficulty in travelling to the dentist by car	6 (10.7%)	0 (0%)	= 0.027
Difficulty in travelling to the dentist by public transport	18 (32.1%)	2 (3.6%)	<0.001

Table 2 Analysis of number of subjects who experienced difficulty in travelling to the dentist according to method of transport.

	Median	25 th Centile	75 th Centile
First AM	1	1	4.75
Mid AM	2	2	4
Post Lunch	3	2	3
Mid PM	4	2	4
Late PM	4	1	5

Table 3 Analysis of preferred appointment times for all subjects

Behaviour	n =50
Crying	39
Self-harming	25
Head butting	20
Biting	16
Spitting	10
Laying on the floor	29
Hitting/ lashing out	37
Positive behaviour	9

Table 4 Analysis of predicted behaviours in ASD group

Activities permitted	Study group n = 56	Controls n = 56	p value
Wearing Glasses	33 (58.9%)	53 (94.6%)	<0.001
Sitting in Chair	32 (57.1%)	51 (91.1%)	<0.001
Air/ water in mouth	19 (33.9%)	46 (82.1%)	=0.002
Mouth Examination	32 (57.1%)	47(83.9%)	<0.001

Table 5 Analysis of activities predicted to be tolerated by all subjects.

Method	n = 56
Speech	38 (67.9%)
Makaton	8 (14.3%)
Picture Exchange Communication System	11(19.6%)
Does not communicate	6 (10.7%)
Other	17 (30.4%)

Table 6 Analysis of methods of communication utilised in ASD group.

	Study group n = 56	Controls n = 56	p value
Photographs of the dental clinic prior to visit	35 (62.5%)	11 (19.6%)	<0.001
Social story of dental visit included with appointment	31 (55.4%)	10 (17.9%)	<0.001
Symbol strip about the dental visit with appointment	31 (55.4%)	6 (10.7%)	<0.001
Photograph of child in dental waiting room or chair	33 (58.9%)	4 (7.1%)	<0.001
Sign “finished” in Makaton when treatment is complete	23 (41.1%)	1 (1.8%)	<0.001

Table 7 Analysis of numbers of respondents who responded favourably to proposed interventions.

	Study group n = 56	Controls n = 56	p value
Monthly	2 (3.6%)	3 (5.4%)	= 1.000
Every 2 months	1 (1.8%)	1 (1.8%)	= 1.000
Every 3 months	27 (48.2%)	7 (12.5%)	<0.001
Every 6 months	23 (41.1%)	43 (76.8%)	<0.001
Other	2 (3.6%)	1 (1.8%)	= 1.000

Table 8 Analysis of frequency of preferred recall intervals

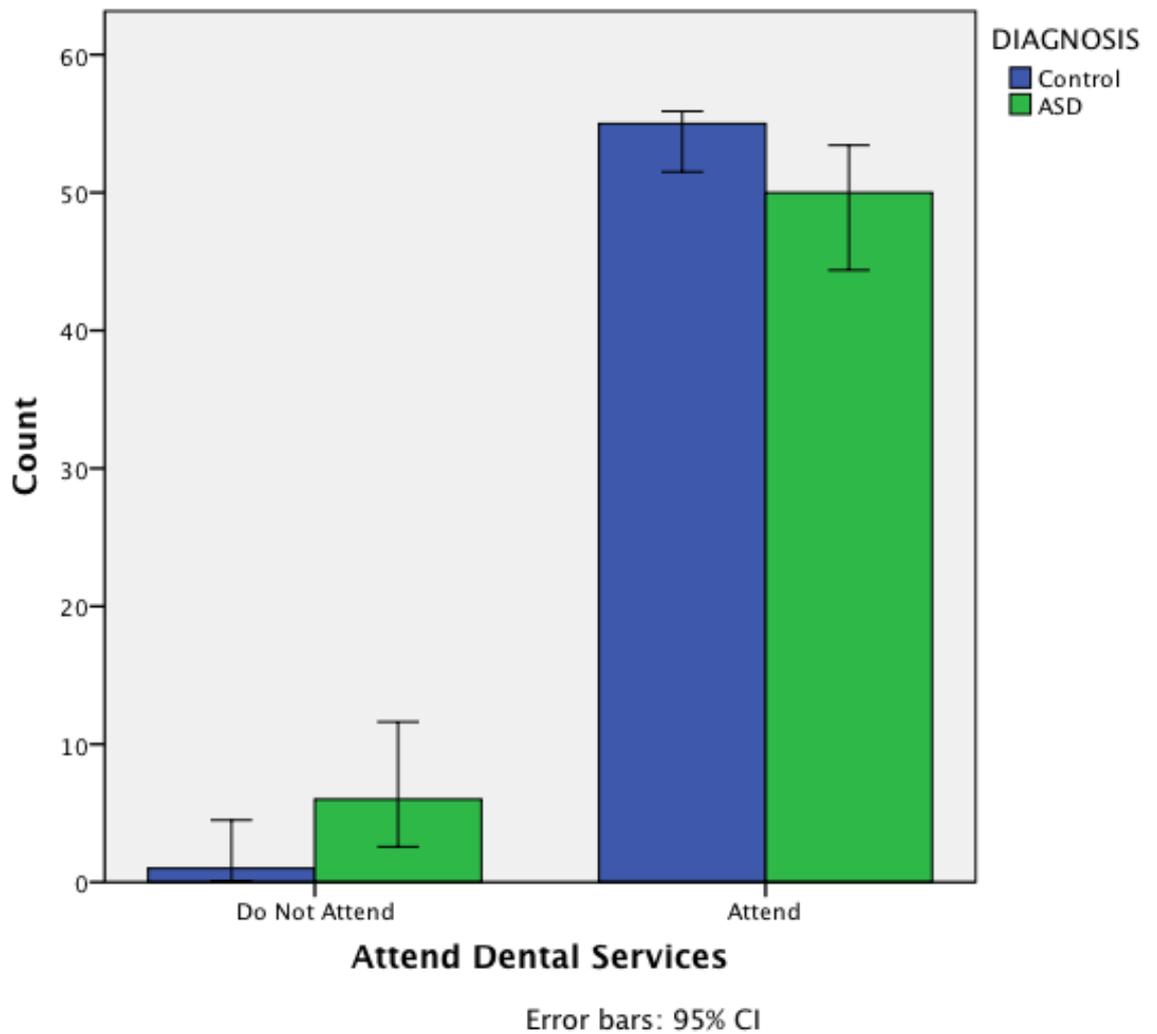


Figure 2. Comparison of attendance at dental services according to diagnosis. Blue bars represent control group and green bars represent the study group. Error bars represent 95% confidence intervals.

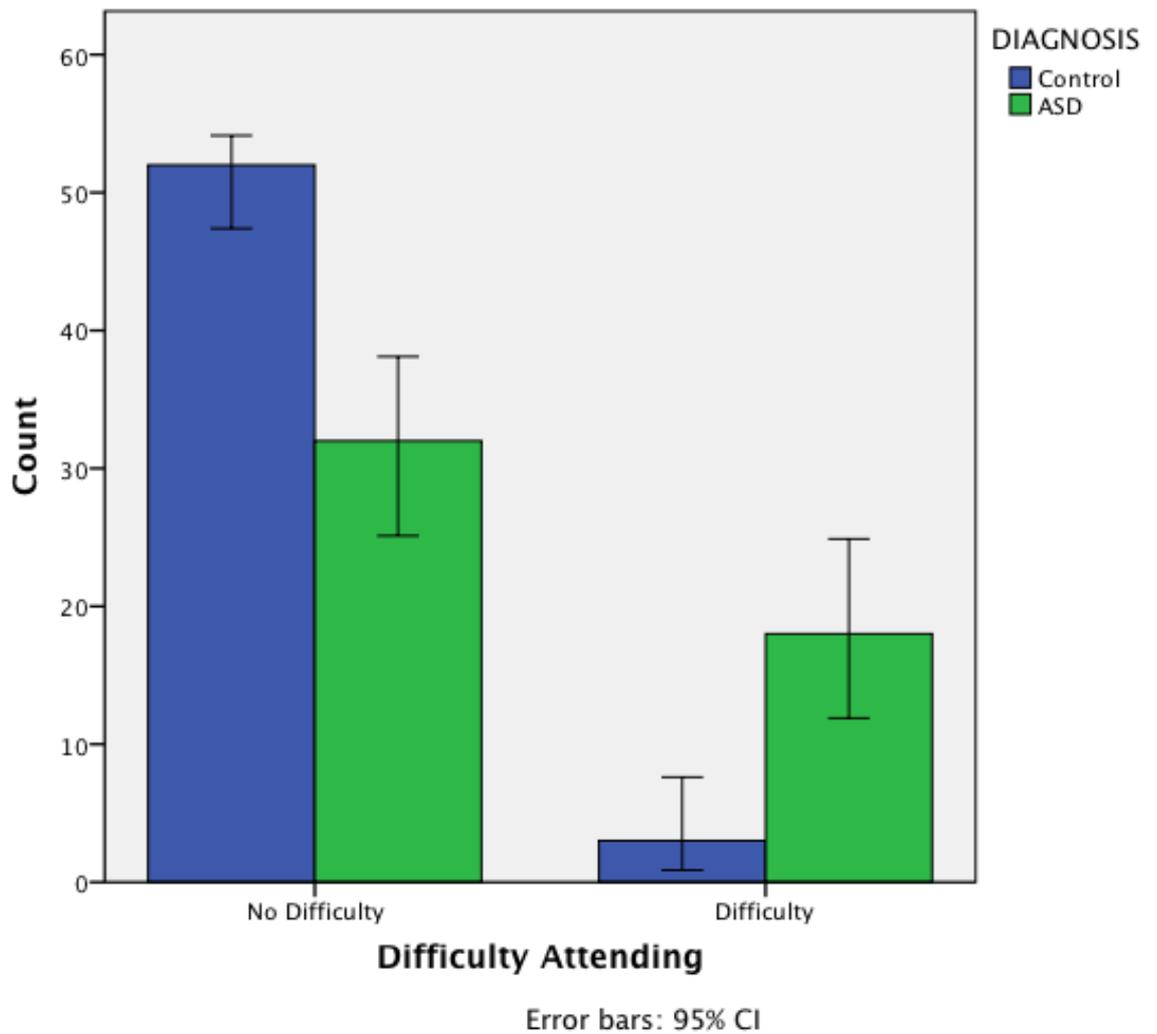


Figure 3. Comparison of expressed difficulty in attending dental services according to diagnosis. Blue bars represent control group and green bars represent the study group. Error bars represent 95% confidence intervals.

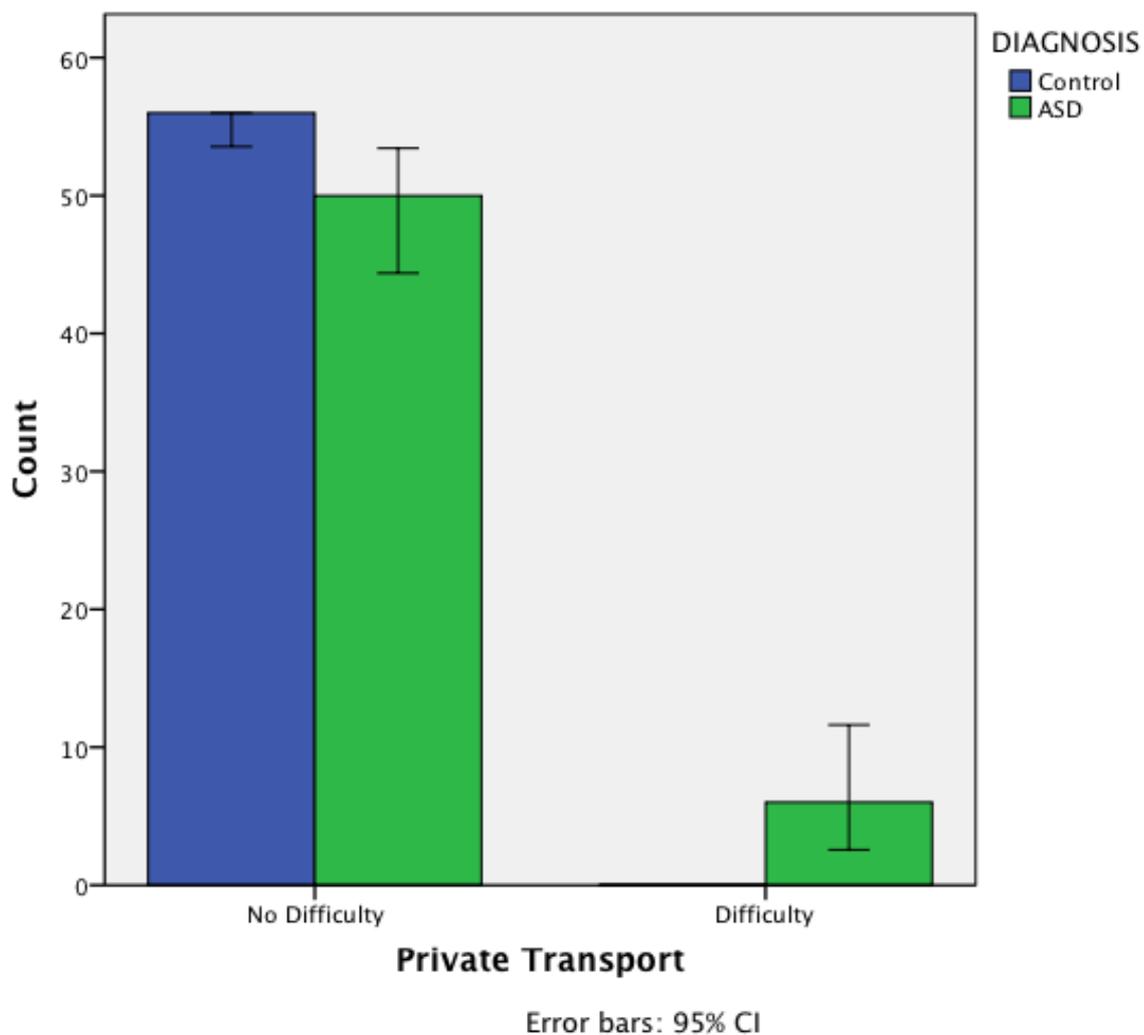


Figure 4. Comparison of difficulty of attending dental services using private transport according to diagnosis. Blue bars represent control group and green bars represent the study group. Error bars represent 95% confidence intervals.

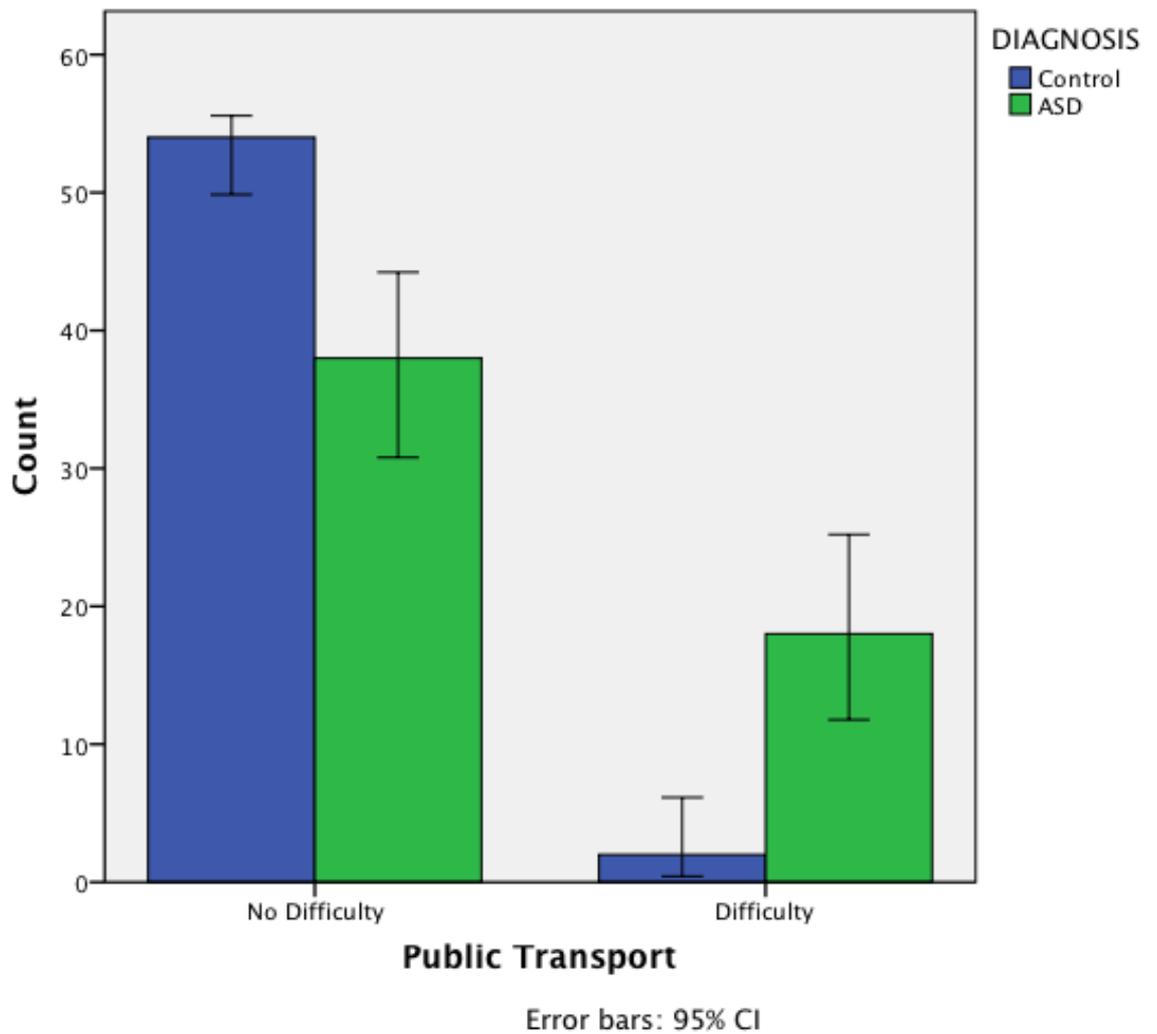


Figure 5. Comparison of difficulty attending dental services using public transport according to diagnosis. Blue bars represent control group and green bars represent the study group. Error bars represent 95% confidence intervals.

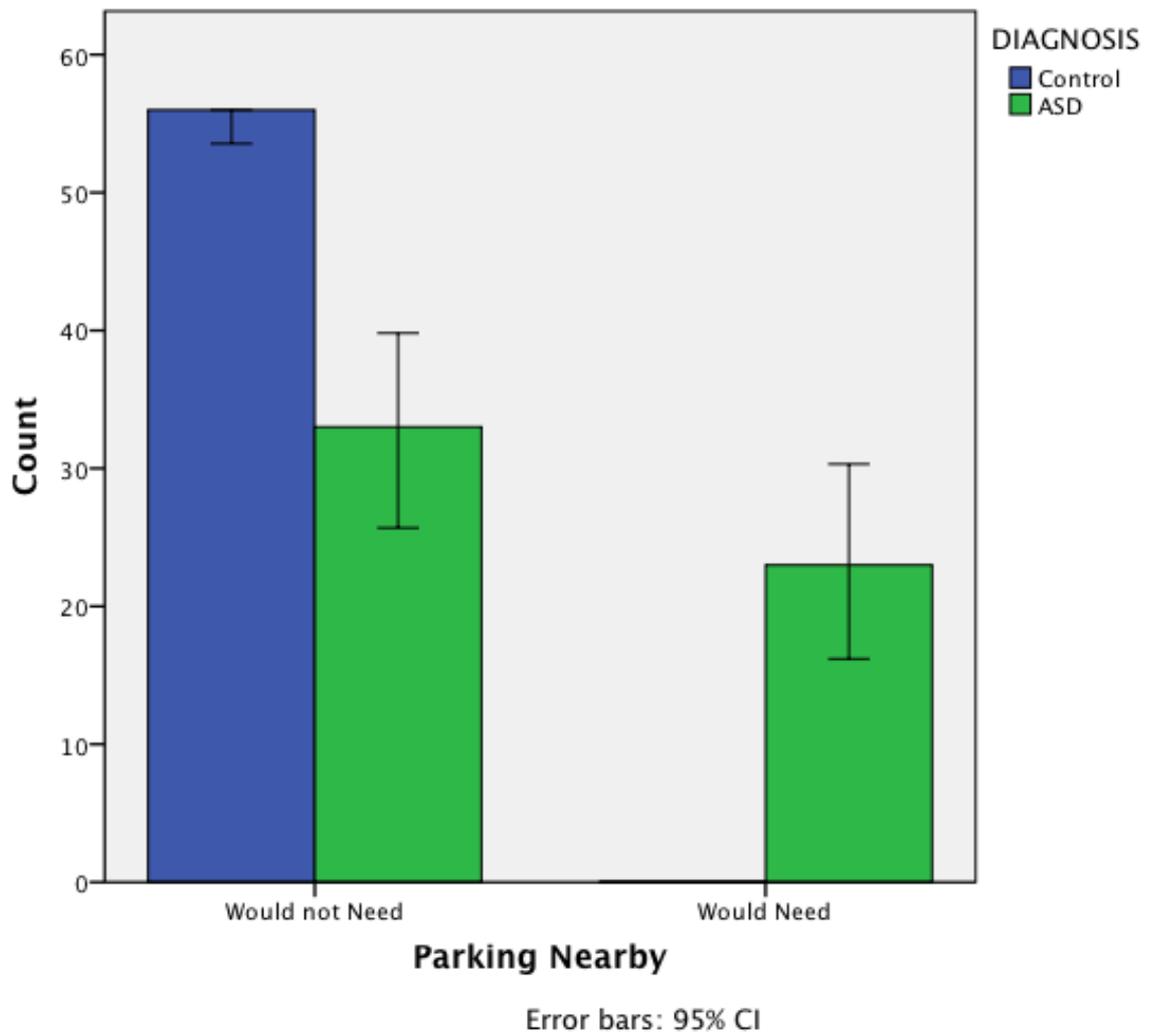


Figure 6. Comparison of need to park close to the dental clinic according to diagnosis. Blue bars represent control group and green bars represent the study group. Error bars represent 95% confidence intervals.

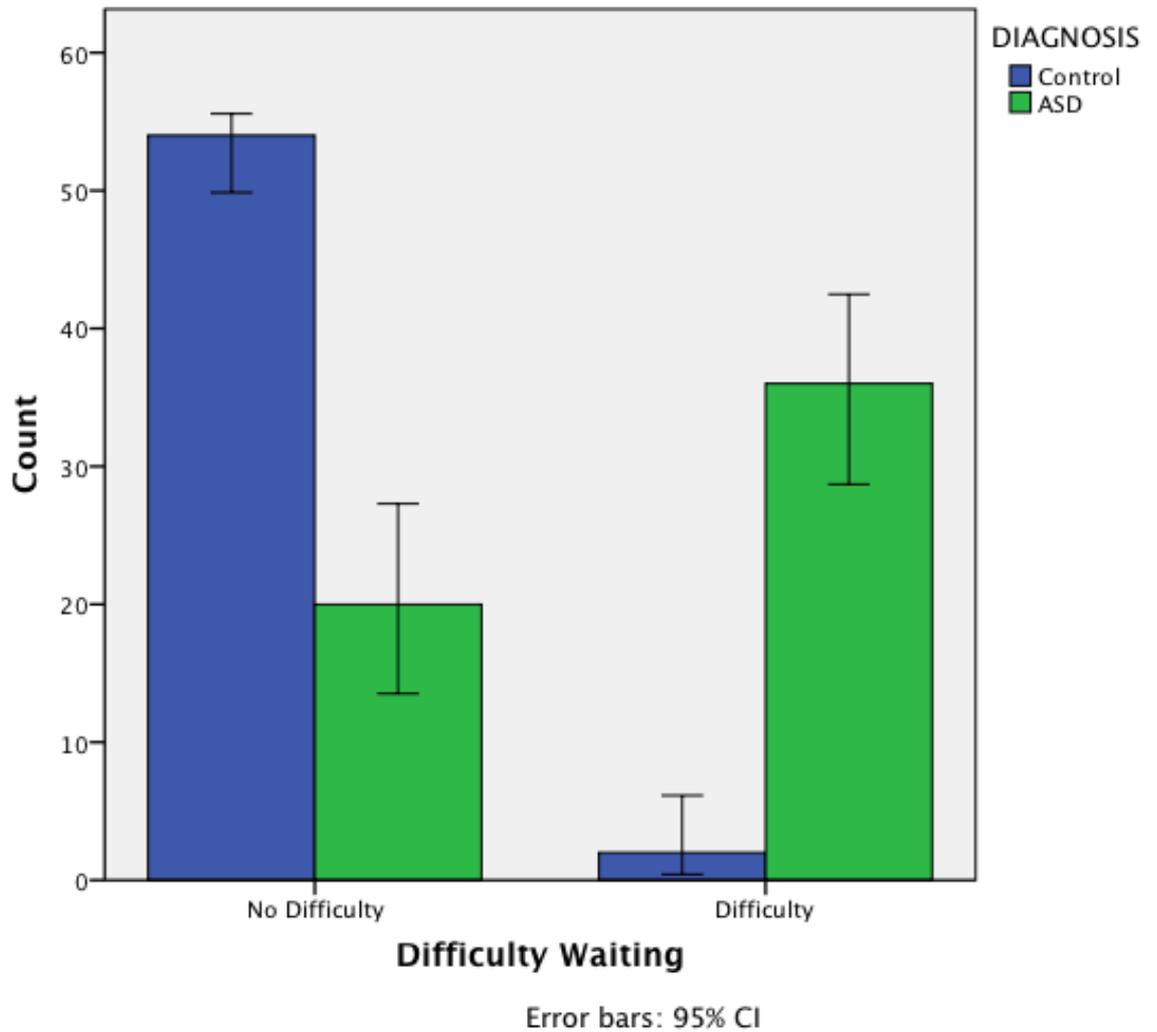


Figure 7. Comparison of anticipated difficulty in waiting in waiting room according to diagnosis. Blue bars represent control group and green bars represent the study group. Error bars represent 95% confidence intervals.

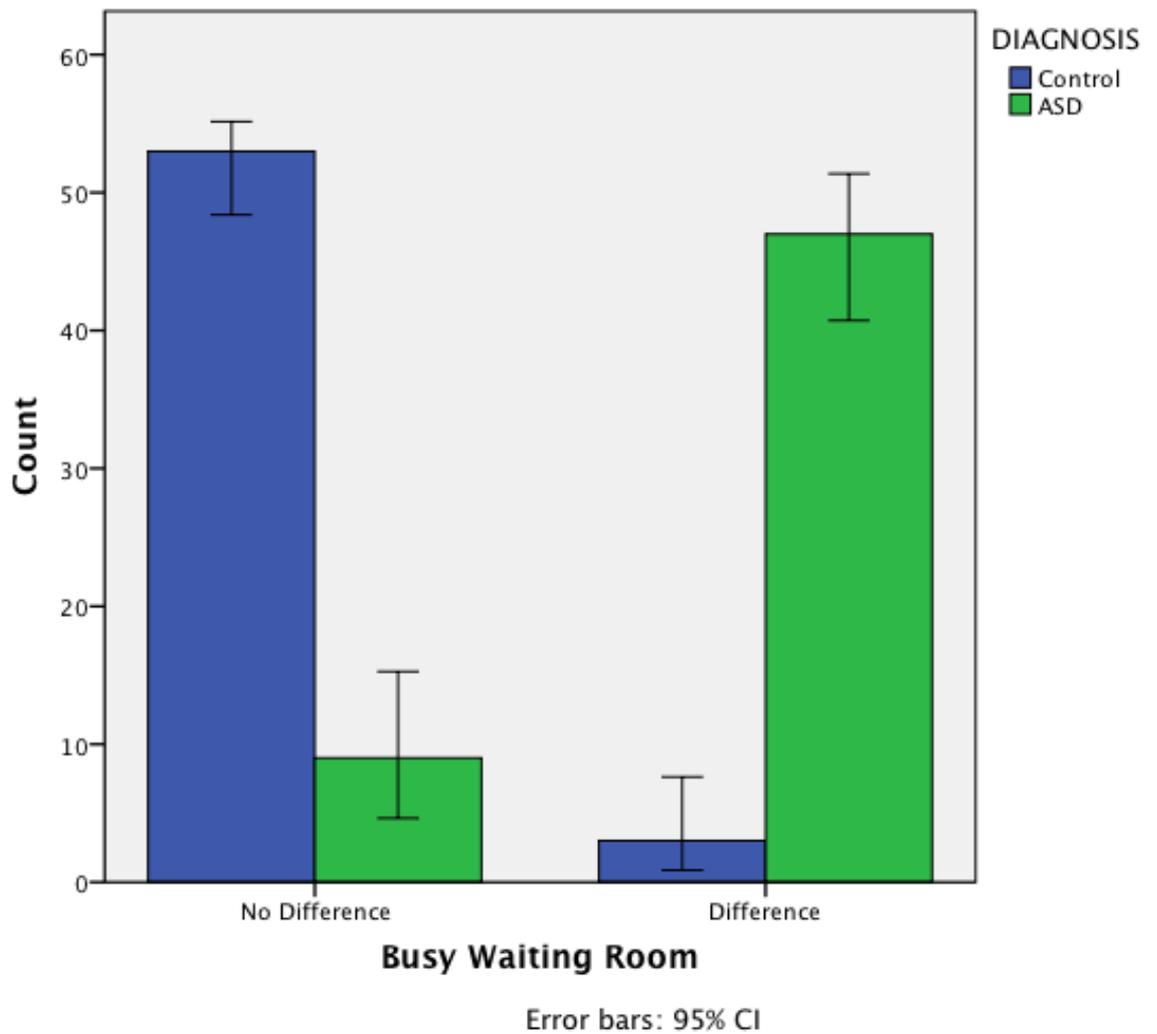


Figure 8. Comparison of anticipated greater difficulty in attendance if waiting room was busy according to diagnosis. Blue bars represent control group and green bars represent the study group. Error bars represent 95% confidence intervals.

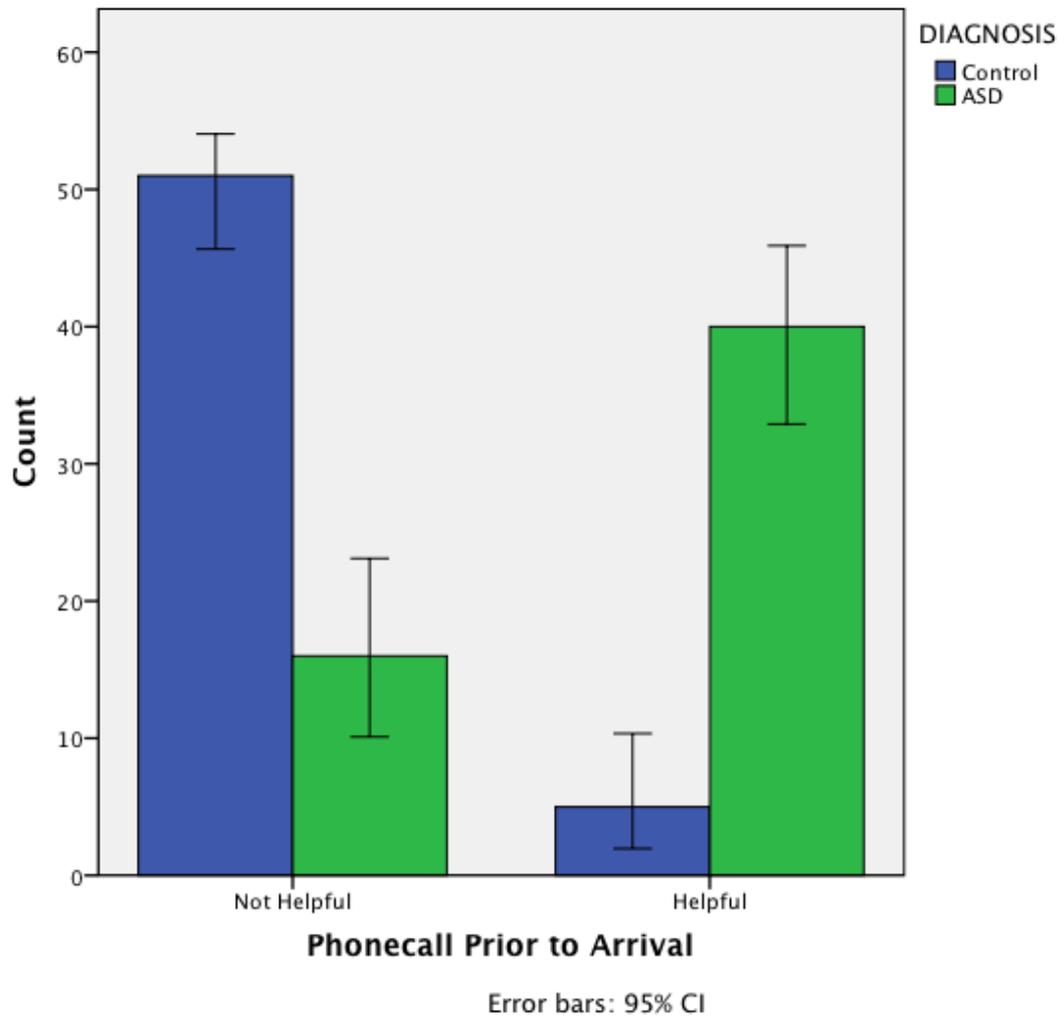


Figure 9. Comparison of anticipated helpfulness of strategy of parents/guardians phoning the dental clinic prior to arrival, to facilitate immediate entry into the dental clinic, according to diagnosis. Blue bars represent control group and green bars represent the study group. Error bars represent 95% confidence intervals.

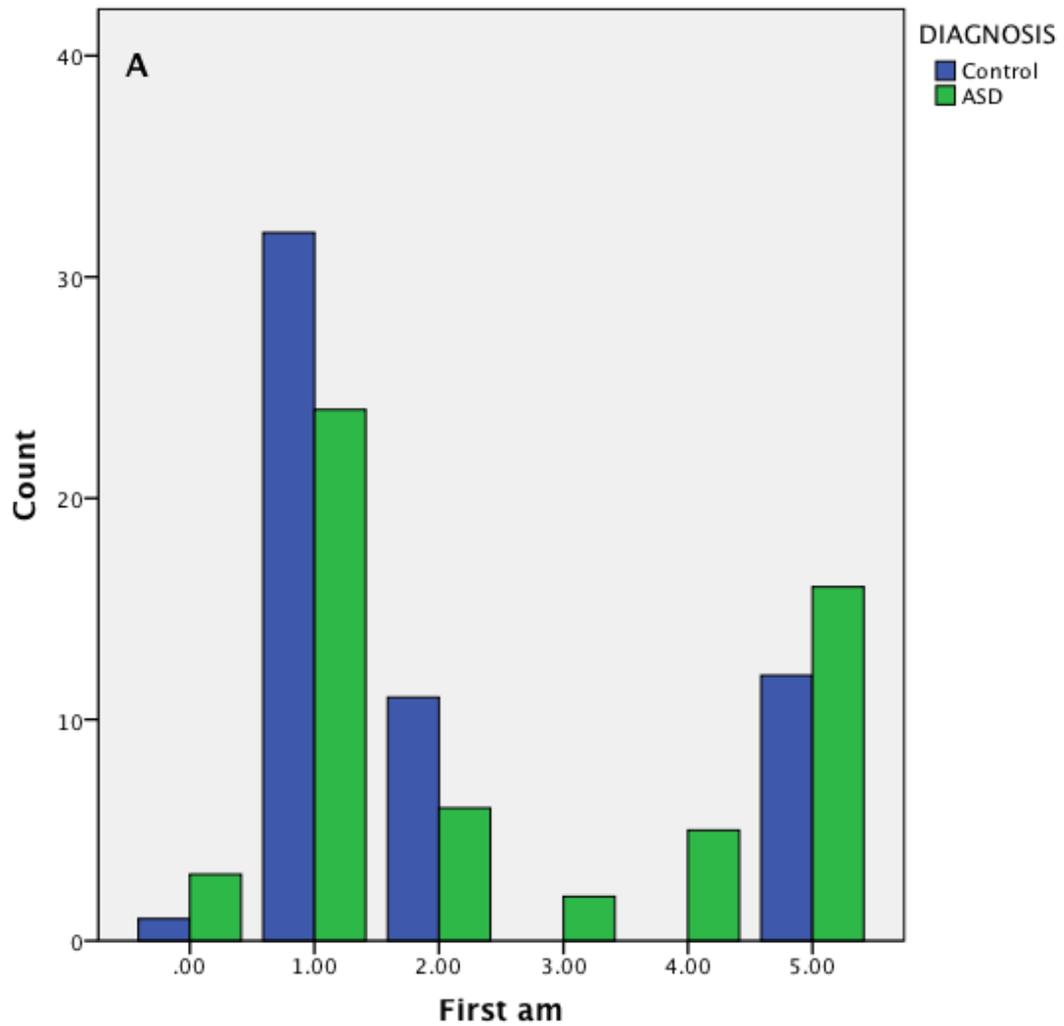


Figure 10 A-E. Comparison of favourable appointment times according to diagnosis. A - Preferences for the first appointment in the morning.

Blue bars represent control group and green bars represent the study group.

Data presented as ordinal data with 1 signifying most favourable appointment time and 5 signifying least favourable appointment time. 0 signifies the subjects who did not enter a preference.

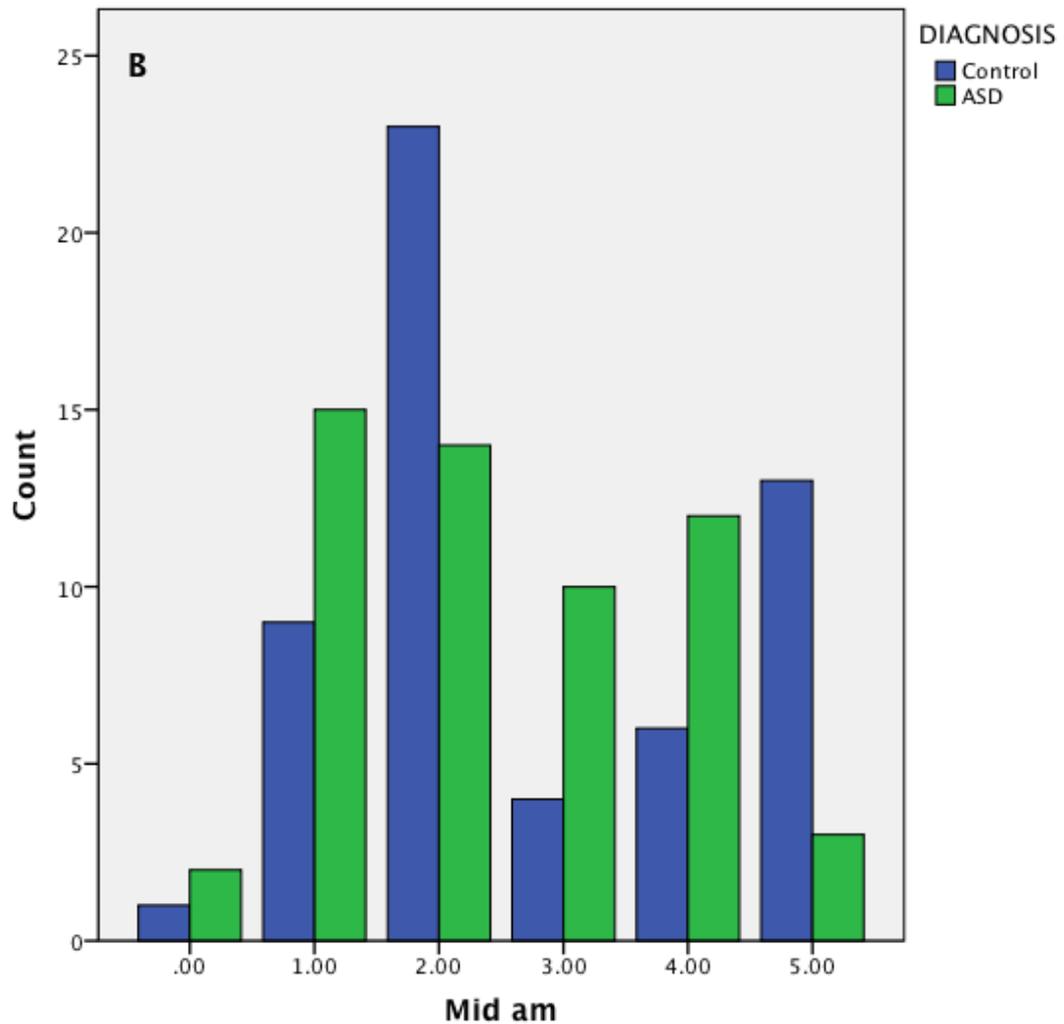


Figure 10 A-E. Comparison of favourable appointment times according to diagnosis. B- Preferences for a mid morning appointment.

Blue bars represent control group and green bars represent the study group. Data presented as ordinal data with 1 signifying most favourable appointment time and 5 signifying least favourable appointment time. 0 signifies the subjects who did not enter a preference.

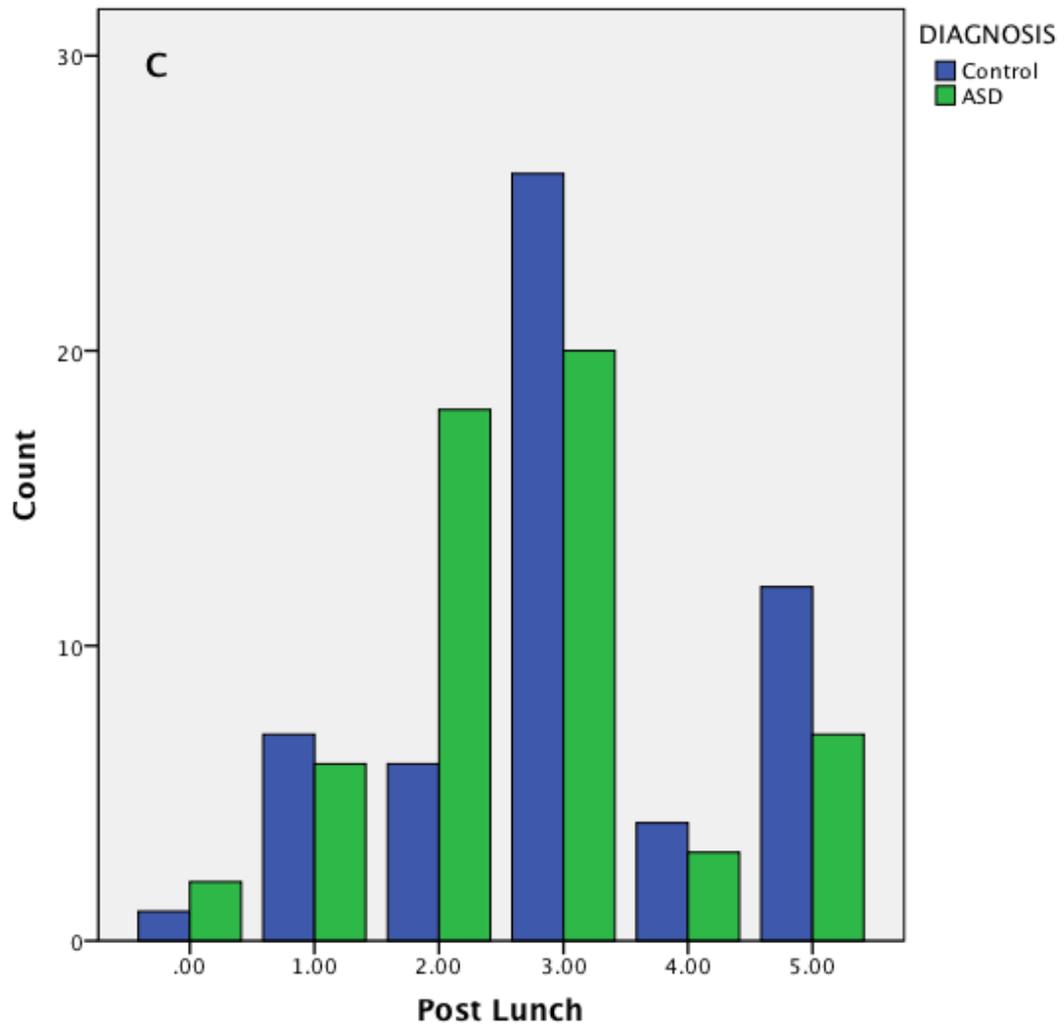


Figure 10 A-E. Comparison of favourable appointment times according to diagnosis. C- Preferences for first appointment post lunch.

Blue bars represent control group and green bars represent the study group.

Data presented as ordinal data with 1 signifying most favourable appointment time and 5 signifying least favourable appointment time. 0 signifies the subjects who did not enter a preference.

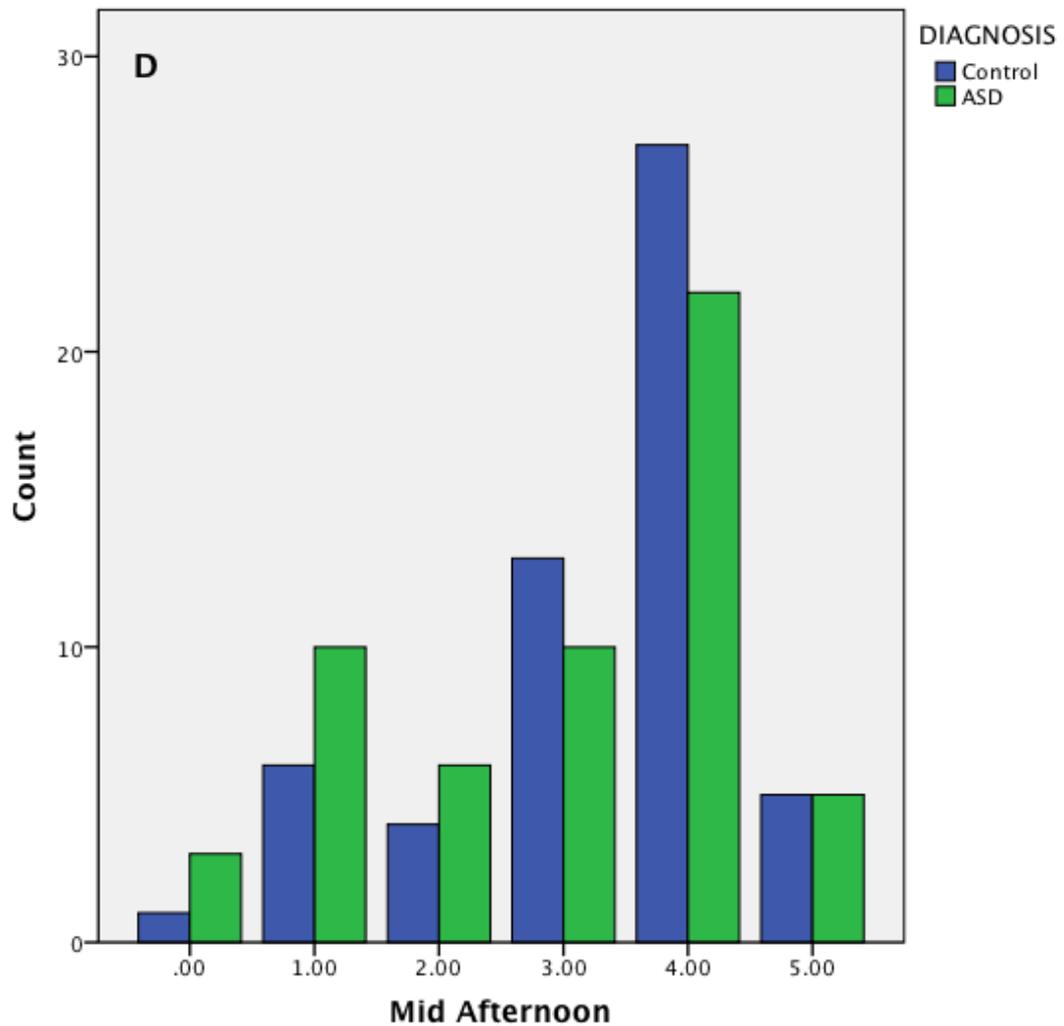


Figure 10 A-E. Comparison of favourable appointment times according to diagnosis. D- Preferences for an appointment in mid afternoon.

Blue bars represent control group and green bars represent the study group. Data presented as ordinal data with 1 signifying most favourable appointment time and 5 signifying least favourable appointment time. 0 signifies the subjects who did not enter a preference.

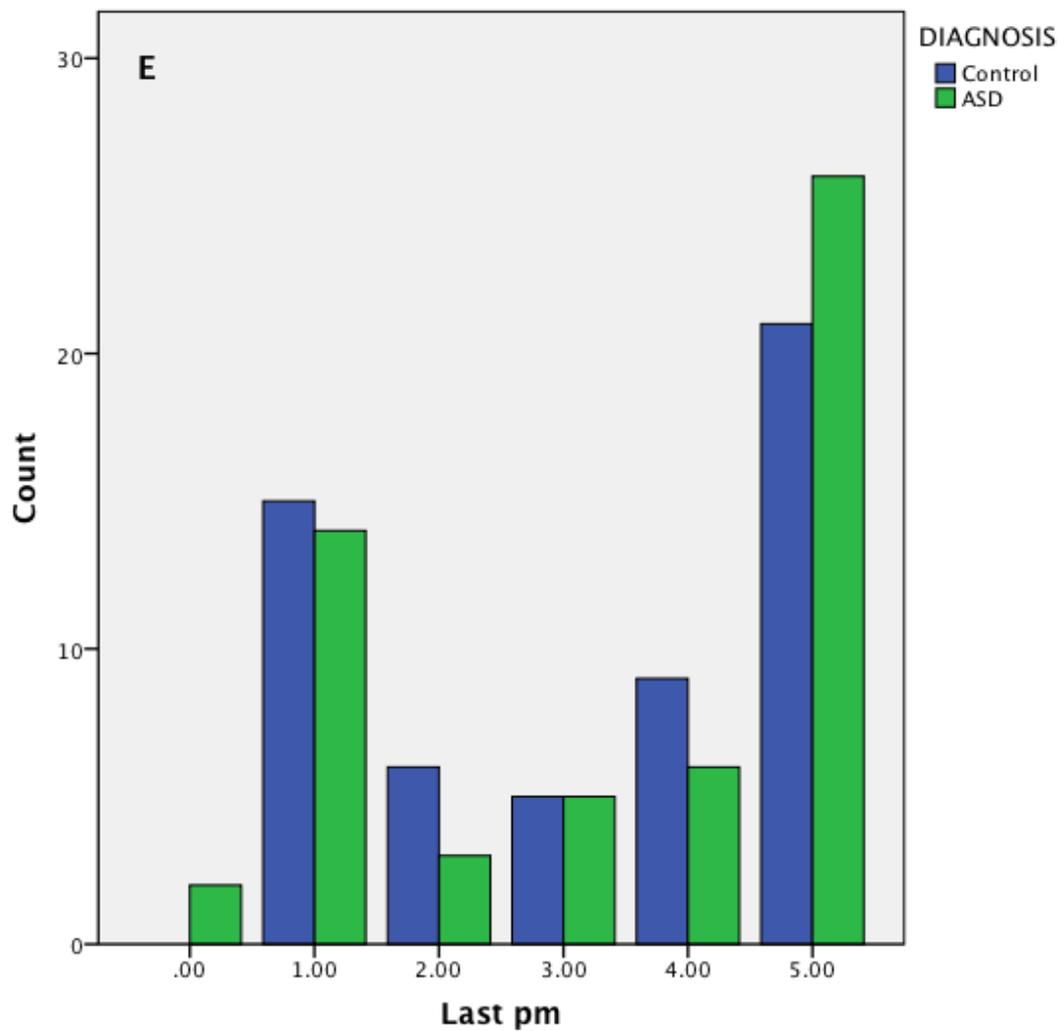


Figure 10 A-E. Comparison of favourable appointment times according to diagnosis. E- Preferences for a late afternoon appointment.

Blue bars represent control group and green bars represent the study group. Data presented as ordinal data with 1 signifying most favourable appointment time and 5 signifying least favourable appointment time. 0 signifies the subjects who did not enter a preference.

7.0 Discussion

7.1 Pilot Study

Results of the pilot study demonstrated numerous potential barriers to dental care experienced by children with ASD in the Hull and East Riding area.

One of the most common barriers to dental care reported was waiting in a busy dental waiting room, which was considered universally problematic by study participants. Parents/carers reported significantly more difficulty in waiting in a busy waiting room than a less busy one, which may reflect the difficulty in social interaction experienced by these children (Myers and Johnson, 2007), or the overstimulation of their sensory responses, with increased perception of touch, smell, sound and vision (Marshall et al., 2008).

A large number of parents/carers reported difficulty in travelling by public transport, while a far lower percentage of those who travelled by car experienced problems. Recent literature suggests that a lower figure of 9% of parents/carers of children with ASD experience difficulties in travelling to the dental office (Nelson et al., 2011).

Half of the children in the study group were reluctant to lie back on the dental chair (n=3) or allow oral examination (n=3). This is consistent with findings by Nelson et al. (2011), who surveyed the parents/carers of 712 children with autism, developmental delay or Down syndrome. They reported that 35% of this group did not tolerate intraoral examination or treatment. These findings also correlate with the results of research into the barriers to dental care for other groups of children with special needs. Al Agili et al. (2004) reported behavioural problems as a barrier to dental care in 41% of patients with cleft lip and palate (CLAP), cerebral palsy (CP), spina bifida and epilepsy/seizure disorders in Alabama. The literature suggests that negative patient behaviour

also represents a barrier to dental care from the perspective of the dentist. In a US survey of general practitioners, 64% cited patient behaviour as a factor affecting treatment (Casamassimo et al., 2004).

7.2 Main Study

This research has examined barriers to dental care for children with autism spectrum disorder. We have established that;

1. Barriers to dental care exist for parents/guardians of children with autism spectrum disorder,
2. These difficulties are manifest throughout the dental experience,
3. Multifaceted solutions will be required to help overcome these potential barriers to dental care for children with ASD.

To examine the question of whether difficulties exist in this patient population, a cross-sectional case-control questionnaire based study was designed. A standard questionnaire was unavailable for the purpose of examining such a question, so it was necessary to construct a questionnaire for this research.

As a result of the pilot study, the wording and structure of the questionnaire was modified. The pilot study informed the final questionnaire and this questionnaire was utilised for the main study. This research has determined that barriers to dental care exist, for parents/carers of children with ASD in the Hull and East Riding area. Participant children in this study demonstrated a male excess, as would be expected when assessing a group of children with ASD. It has been estimated that males are affected by ASD in the order of 5 times more frequently than females (Centres for Disease Control and Prevention, 2012).

7.2.1 Attendance at Dental Services

It is important to note that there was no significant difference in dental attendance between study and control groups, although there was a slight numerical increase in the number of children within the control group who accessed dental care. This indicates that the study group children are accessing dental care, despite the perceived barriers described. Given the methodology of this research, this is not an unexpected finding. The majority of parents/carers recruited to the study group were selected from those whose children attend dental services. As such, this may be considered a limitation of this research, as this population may not be entirely representative of the ASD population as a whole. However, this group of parents/carers may be best placed to report barriers to dental care for their children, as they will have experienced barriers, rather than reporting perceived barriers. In an effort to identify barriers in the population who did not attend dental services, some parents/carers of children with ASD, who attended special schools in the Hull and East Riding area, were recruited to the study group. However, the high rate of reported attendance at dental services amongst this group may indicate responder bias. The finding that the majority of parents/carers of children with ASD access dental care for their children is similar to recently published literature. Lai et al. (2012) reported that the majority (93%) of parents/carers of children with ASD were able to access dental care for their children. Parents/carers whose children did not access dental care described the problems associated with finding a dentist with the specialist skills involved in treating a child with ASD. They suggested that this might be due to reluctance by dentists to treat children with ASD, a lack of appropriate training in this area or a combination of both. This is in accordance with the literature, which has

reported for many years that dentists experience considerable barriers providing quality dental care, to children with special health care needs. It has been suggested that dental practitioners are unwilling, or unable to provide this necessary care, due to financial or training constraints (Siegal, 1985). Review of current literature also suggests evidence for lack of remuneration as a barrier to dental care for children with special health care needs (Al Agili et al., 2004). It was shown by Weil and Inglehart (2010) that only 32% of general dental practitioners (GDPs) versus 89% of paediatric dentists were willing to treat a patient with ASD. In this questionnaire study, GDPs indicated that their undergraduate dental training had been insufficient to prepare them to treat patients with ASD. Respondents who felt better trained were more likely to treat patients with ASD. Similarly, Smith et al. (2006) found that both dental students and alumni felt undertrained to treat under-served patient groups, with fewer than 50% of undergraduate students planning to treat patients with disabilities. Educational experience of undergraduate dental students was again shown to correlate well with their proposed willingness to treat patients with disabilities by Dao et al. (2005). Romer et al. (1999) reported that just over half of dental schools in the USA and Canada provided less than five hours of structured training in special needs dentistry. Wolff et al. (2004) advised the introduction of increased undergraduate training in special needs dentistry combined with a robust programme of continuing dental education, to prepare students to treat a more diverse group of dental patients.

It may be appropriate to deliver some targeted teaching to GDPs in the area of Hull and East Riding, to increase their knowledge base regarding ASD. It is clear that the number of specialist paediatric dentists in the UK is insufficient to

treat every child with ASD and we will need to revisit the idea of specialist only care for this group of patients.

There was an apparent lack of awareness amongst some parents/carers in the study group, regarding the availability of a Consultant Paediatric Dentist in the Hull and East Riding area. It would be appropriate to discuss the referral pathway for patients with ASD to the Consultant Paediatric Dentist with GDPs in the area, and to reiterate appropriate referral guidelines for these patients.

There was a significant difference between study and control groups in the number of parents/carers who perceived difficulty in accessing dental care for their children, with 39% of the study group reporting barriers to dental care. Looking at specific comments by parents/carers, the most frequently perceived barrier to dental care was difficulty in finding a dentist, as 9 parents/carers identified this as potentially problematic. The patient's negative behaviour (6 parents/carers) was quoted as a potential difficulty. Parents/carers also commented on the perceived difficulty involved in waiting in the waiting room, the short appointment time allocated and the dentist's lack of appropriate training. As previously outlined, this information is in accordance with published literature.

Parents/carers in the study group cited negative behaviour as a reason for failing to access dental care for children with ASD. Again, this concurs with published literature. Lai et al. (2012) undertook a study of parents/carers of children with ASD from the North Carolina Autism registry. This was a postal questionnaire study, which investigated both unmet need and barriers to dental care for children with ASD. The authors reported that 12% of children with ASD had unmet dental needs. The most frequently reported barrier to dental care in this group was lack of cooperation by the child (60%). Children with

poorer perceived behaviours had increased odds of having outstanding dental issues. Brickhouse et al. (2009) reiterated the finding that uncooperative behaviour by children with ASD impacted negatively on their access to dental care.

7.2.2 Transport to Dental Services

Transport to the dental surgery represented a significant difficulty for parents/carers of the study group. Transport problems were subdivided into private transport and public transport to the dental clinic. In the first instance, 10% of the study group felt that travel by car would represent a difficulty for their child, but there was no suggestion in the control group that this would be the case. The study group listed long distance and uncertainty about the purpose of the journey as reasons for this difficulty. Three parent/carers indicated that they did not have a car. A higher number of the study group (n=18) indicated that public transport was a perceived barrier for their child. Interestingly, two parents/carers in the control group marked public transport as a potential barrier, although only one parent elaborated further on this point, by criticising the long journey involved. The reason that public transport represented a barrier to dental care for the second parent/carer's child is unclear.

It is noteworthy that recent literature has reported similar findings regarding transport barriers to dental care for children with ASD. In a study by Lai et al. (2012), 10% of parents/carers of children with ASD, in the North Carolina region of America indicated that transport to the dental surgery was a barrier to dental care for their children. This was a questionnaire study, with large numbers (n=555) although the results are limited by the absence of a control group. In contrast, Brickhouse et al. (2009) undertook a questionnaire study (n=55) to

investigate possible barriers to dental care for children with ASD in the Virginia area of America. Parents/carers indicated that transportation to the dental surgery was not a potential barrier to dental care for this group. This may be due to the sourcing of the study group from the Autism Program of Virginia's mailing list. This is an organisation that parents must actively request membership of, and may be therefore biased towards those from a higher socioeconomic status. The finding that most of the participant children in this study were from families with higher than average incomes strengthens this theory. Therefore these results are not necessarily generalisable to less affluent populations. The determination, by Lai et al. (2012) of transport as a potential barrier to dental care is an expected finding in a country as geographically vast as America, and it is interesting to note from the results of this study, that transport may represent a similar barrier to dental care for children with ASD in America and the UK.

A significantly higher number of parents/carers in the study group reported that parking close to the dental clinic would be potentially beneficial for their child (23 versus 0). This is an unexpected finding, as the patients with ASD in our study did not have any additional co-morbidities, such as physical disabilities. The parents/carers in the study group did not clarify the reasons for this, but it may be due to reluctance by study group children to enter the dental clinic.

7.2.3 Inside the Dental Surgery

Waiting in the dental waiting room was deemed to represent a potential barrier to dental care by a significantly higher number in the study group (n=36) than in the control group (n=2). This effect was exacerbated if the waiting room was busy. A qualitative section in the questionnaire further enabled the examination

of this barrier. Parents suggested that the ability to wait in the waiting room might be dependent on the child's mood, the size of the waiting room and the length of waiting time. Four respondents specified that prolonged waiting would increase the risk of behavioural problems but did not specify information following this. Interestingly the number of respondents who expressed a difficulty in waiting appears to be higher than those revealed in other studies. Lai et al. (2012) reported, from the results of a mailed questionnaire that 13.8% of patients with ASD experienced difficulties while waiting for dental treatment. The difference between these two results is unclear. It may be that in the study by Lai et al. (2012), a documented difficulty with waiting in the previous 6 months was assessed, whilst this study examined perceived difficulties. It could be suggested thus that the perceptions of those parents and carers in our study group may be overstating the risks involved in waiting, for these children. However, examining perceived difficulties is no less relevant as it may be the perception of difficulty that leads to a barrier to care. It also must be stated that these perceived difficulties were founded on parent's/carer's previous experience with the care of the child, and thus there may in fact be a fundamental difference between the populations examined by Lai et al. (2012) and the current research.

It is not clear why parents/carers in the control reported difficulty in waiting in the waiting room (n=2), which was heightened by a busy waiting room (n=3). It may be that these parents/carers were simply reporting a reluctance to wait beyond their appointment time, rather than the possibility of negative behaviour by their children.

7.2.4 Strategies for Accessing the Dental Surgery

Phoning the dental clinic prior to arrival, to allow immediate access to the dental surgery was reported to be potentially helpful by a significantly higher number in the study group (n=40) than control group (n=5). This finding is to be expected, given the reported difficulty with waiting in the waiting room. It is surprising that we didn't see universal affirmation of this as a potentially beneficial intervention, within both groups. It may be that study participants rightly interpreted this as an intervention necessary to reduce negative behaviour in the patient, rather than a convenience for the parent/carer. This finding is unique to this research, and represents an important potential intervention to help reduce barriers to dental care for this group of patients.

The preferred timing of the dental visit was variable amongst the two groups. However, a significantly higher number in the study group preferred an early morning appointment, in comparison to the control group. The reasons for this were not revealed, but it may be that negative behaviours are less in the study group in the early morning, before they become tired. It was a surprising finding that appointments in the late afternoon were the least popular with both groups, as anecdotally these after-school appointments have been popular with parents.

It is significant that almost 90% of parents/carers in the study group versus 10.3% in the control group felt that their child's behaviour was liable to change without warning. This correlates with recent literature. Lai et al. (2012) reported that patient's behaviour (60%) was the most common barrier to dental care in their study group, as reported by parents/carers, although this study did not specify which behaviours in particular were deemed to be problematic. Brickhouse et al. (2009) reported that the patients' behaviour in the dental

surgery was significantly associated with their inability to access dental care during the preceding year. Patients who exhibited “extremely, uncooperative behaviour” were less likely to have a dental home than those who did not behave negatively in the dental surgery. Similarly, Nelson et al. (2011) undertook a combined postal/telephone questionnaire for parents/carers of children with special healthcare needs. They noted that 30% of participants in the ASD/Down Syndrome/Developmental delay group considered their child’s behaviour to be a potential barrier to dental care. Even though these results are not subdivided, it lends additional credence to the notion that negative behaviour is a perceived barrier to dental care for children with ASD.

It is noteworthy that loud noise was considered to be a universal trigger for negative behaviour in the study group. It is well established that patients with ASD may demonstrate an abnormally enhanced perception of auditory stimuli, leading to intolerance of loud noise (Rapin, 1991). This was confirmed by the more recent work of Tomchek and Dunn (2007). This group undertook a retrospective examination of the medical notes of 281 children with ASD between 3 and 6 years. They reported that 95% of a group of children with ASD demonstrated sensory abnormalities to some extent, with 50.9% showing heightened sensitivity to unexpected loud noise. In the dental setting, loud noise may be encountered within the waiting room, the ringing of a telephone in reception, or the use of hand pieces within the surgery, leading to multiple potential triggers for negative behaviour.

It was not anticipated that parents/carers in the control group would identify loud noise as a potential trigger to negative behaviour for their children, and the reason for this is unknown. The control group was recruited from a population of healthy, neurotypical children, who had been referred to a Consultant led

specialist paediatric dental service. A high proportion of these children were referred for behaviour management, and it is theorised that parents/carers may have been concerned that loud noise would trigger increased dental anxiety in their children.

Parents/carers in the study group identified a range of potential trigger factors for negative behaviour in their children. This was an expected finding, as sensory abnormalities in patients with ASD have been found to be multiple, and pervasive across the age and severity spectrum of ASD (Leekam et al., 2007). Strange taste and smell were noted by an equal number of parents/carers to be potential trigger factors (n=46). Aberrations of taste and smell in patients with ASD are well recognised in the literature. Rogers et al. (2003) investigated sensory abnormalities across a range of toddlers with ASD and those with other developmental delay, as reported by parents/carers. They noted consistently elevated sensory responses in the ASD group, particularly in response to taste and smell.

Head touching was identified as a potential trigger factor for negative behaviour by 44 parents/carers in this study. Published literature concurs with this finding. While light touching may activate the nervous system in children with ASD, leading to intense feelings that can be overwhelming, the advantages of deep touch pressure to produce a calming effect have been reported (Grandin, 1992; Zissermann, 1992). This information has been extended by Lindemann and Henson (1983), who demonstrated that children with ASD appeared to be comforted by physical restraint.

Bright lights were perceived as potential triggers of negative behaviours by 44 parents/carers in the study group. Sensitivity to bright light was also demonstrated in the ASD group, by Tomchek et al. (2007), with the finding that

16% of children remained hypersensitive to light, even after others had adapted to it. This is particularly relevant to the dental experience, as a dental examination is reliant on the use of the dental light.

Enclosed spaces represented a potential trigger for negative behaviour for 43 of the study group children. This potential claustrophobia has not, to our knowledge been previously reported in the literature. It would be beneficial for the dentist to be aware of this potential trigger for negative behaviour, particularly if several differently sized surgeries are available.

The revelation by parents/carers that numerous trigger factors for negative behaviours exist for children with ASD, and the specification of the most prevalent factors are important findings of this research. It would be advantageous for the dentist to be aware of potential trigger factors for negative behaviour in the patient with ASD. The recognition of same may allow the dentist to circumvent some of the hazards involved in the dental experience for these patients. Parents/carers described in detail the potential behaviours that their children might display. There was a significant difference between study and control groups in the predicted likely behaviours. The only predicted behaviour in the control group was crying, which was anticipated by relatively few parents (n=7). This is to be expected given that the control group was sourced from a group of potentially anxious patients, as previously stated. It is perplexing that no parent/carer in the control group anticipated that their children would display positive behaviour. This may be due to poor layout of the questionnaire, as the option for positive behaviour was listed after numerous negative behaviours. Parents/carers may have left the section blank, having assumed that all the options in this section related to negative behaviours only.

Crying was the most commonly predicted negative behaviour in the study group (n=39). This was followed hitting/lashing out (n=37) and self-harming (n=25). Lecavalier (2006) also reported the prevalence of negative behaviours, in a questionnaire survey of 353 parents of children with pervasive developmental disorders. 15.9% of parents predicted that their child might hit, while 11% predicted self-injurious behaviour. It is unclear why the prevalence of predicted negative behaviours was higher in the present study. It may be due to the wider age range of study group children in the Lecavalier (2006) study (3-21 years versus 3-16 years in the present study). Also, parents/carers in the Lecavalier (2006) study reported on the prevalence of negative behaviours by their children in general, whereas the present study asked parents/carers to predict negative behaviours that their children might display in the dental surgery. It has been recorded in the present study that numerous trigger factors for negative behaviour in children with ASD exist within the dental surgery, and this may explain the increased prevalence of expected negative behaviours in comparison to those recorded by Lecavalier (2006).

Lying on the floor was another commonly predicted behaviour in the ASD group (n=29). This is a very useful finding, and has not, to our knowledge been reported previously in the literature.

Lecavalier (2006) reported that 9.9% of a group with pervasive developmental disorders were predicted to attack people, as ascertained by questionnaire survey of their parents. While this is in accordance with the present study, it is noteworthy that the questionnaire in our study asked parents/carers to subdivide potential "attacking" behaviour into specific behaviours. This is advantageous information for the dental practitioner to have in advance of the

dental visit. It may allow the patient to be appointed at a quiet time, to decrease the risk of injury to patients, carers and dental staff.

These predicted specific behaviours included head butting, biting and spitting. Twenty parents made a prediction of head butting, which is an interesting finding as this behaviour may potentially result in quite a serious injury to patients in the waiting room, parents/carers or to the dental staff. This information, as with the prediction of lying on the floor is a novel finding in the literature.

Biting (n=16) and spitting (n=10) were predicted behaviours by a number of parents. Although anecdotal evidence has long suggested that this may be the case, this is the first evidence, to our knowledge that confirms this specific behaviour.

In addition to predicted behaviours listed in the questionnaire, parents/carers listed further possible negative behaviours that may be displayed. These included screaming, shouting, trying to escape and confusion.

One predicted behaviour involved, "speaking in a funny voice". This finding is in agreement with recent literature. Sharda et al. (2010) compared speech intonation in 15 children with ASD to age matched controls. They found that the ASD group demonstrated an elevated pitch with exaggerated intonation of speech. McCann and Peppé (2003) agree that many individuals with ASD demonstrate abnormal prosodic expression, involving slow speech, fast speech or the adoption of an unusual accent.

Looking at the predictions for positive behaviour, it was encouraging to note that some parents (n=9) indicated that their children might display positive behaviour within the dental surgery. This information would be particularly useful for the dentist prior to the patient's first dental visit.

Given the vast range of predicted negative behaviour in the ASD group, it was not surprising to find that behaviour management techniques were utilised by a significantly higher number of parents in this group. These behaviour management techniques were diverse, as enumerated in the results section.

ASD represents a group of disorders remarkable for its considerable heterogeneity, and there remains to date, no universally accepted behaviour management strategy for this group (Warren et al., 2011). Behaviour analysis involves the study of variables that influence the behaviour of an organism. When this analysis is conducted outside of a laboratory, and applied to questions of social relevance, it is termed “applied behaviour analysis” (Baer et al., 1968). Lovaas (1987) introduced the notion of applied behaviour analysis (ABA) as a behaviour modification technique for children with ASD, often termed the, “Lovaas-based approach” (Warren et al., 2011). This intervention was based on the premise that neurotypical children learn constantly from the environment, in contrast to children with ASD, who do not comprehend their environment. Children with ASD in this study (n=19) were treated during their waking hours, with techniques such as, “ignoring behaviour” and taking a “time out” if negative behaviour was displayed. Positive behaviour was rewarded with a reinforcer. A control group was recruited from a group of children with ASD who did not receive behavioural intervention, or received less intensive interventions. This study reported that almost 50% of the study group achieved normal educational and intellectual function, in contrast to 2% of control group participants. This seminal publication was the first to suggest that ASD could be treated, and represented the initiating factor for an abundance of research on the topic. Research has shown that ABA is a commonly used behavioural modification tool, among parents/carers of children with ASD. Goin-Kochel et

al. (2006) undertook a web-based survey of parents of children with ASD, and reported that 55.2% of this group (n=479) utilised ABA therapy in the treatment of their children.

The use of a social story™ to teach appropriate social behaviour to children with ASD is well documented in the literature (Quirnbach et al., 2009). This is in response to a growing understanding by researchers, that the child with ASD is unable to “read” or understand social situations. A social story™ is a short story, written for an individual child, describing a specific activity, and the expected behaviours associated with that activity (Gray and Garand, 1993). They can help the patient with ASD to understand challenging social situations (Sansosti et al., 2004).

Numerous different types of social story™ have been described including descriptive, perspective, affirmative and directive stories (Crozier and Tincani, 2007). A descriptive story includes a description of the appropriate steps involved in particular social situations. A perspective story contains information regarding the feelings and emotions of others. An affirmative story will reassure the reader and a directive story will give instructions about what the child should do (Crozier and Tincani, 2007).

Santosi et al. (2004), undertook a literature review, examining the effect of social stories™ for the education of children with ASD. This review concluded that there is some tentative evidence in the literature for the effectiveness of the social story™ as a behaviour instruction tool for children with ASD. This evidence should be interpreted with caution however, due to the paucity of experimental design, weak treatment outcomes and the number of possible confounding factors, which may have influenced behaviour change. While the literature weakly endorses the idea of the social story as a behaviour guidance

tool for the child with ASD (Santosi et al., 2004), parents/carers in this study have indicated that the social story would be a helpful adjunct to the dental visit for their children.

The use of “stop signals” was listed as a behaviour management technique by 2 parents/carers. Stop signals refer to the use of a red “stop sign” picture to indicate to the patient that they must desist from a particular behaviour. There is scant evidence in the literature that stop signals are effective to prevent negative behaviour in the patient with ASD. It has been shown that the use of a stop sign was advantageous in helping to stop a hand flapping habit in a patient with ASD (Ringdahl et al., 2002). However, this was a report of one case only, and verbal reminders from a therapist augmented the use of the stop sign. It is also important to note that hand flapping continued in the absence of the therapist, even in the presence of the stop sign.

Talking calmly to the patient, using basic instructions and explanations was documented as a behaviour management technique by 9 parents/carers. These parents/carers suggested that talking in a reassuring manner, using “one word or two word phrases”, or “positive, happy language” was their preferred technique. It is well acknowledged in the literature that children with ASD demonstrate difficulty with expressive and receptive speech, with one third (Bryson, 1996) to one half (Lord and Paul, 1997) failing to develop adequate speech to meet their daily requirements. Both high and low functioning children with ASD have been shown to perform poorly in complex language tasks, involving figurative speech and comprehension (Noens et al., 2006). This may be due to poor central coherence, which is the ability to process incoming information rapidly, in the correct context, and elucidate a higher meaning (Happé, 1996). This apparent failure to process incoming stimuli may explain

the parents/carers preference for simple language, when communicating with study group children.

Two parents/carers specifically discussed the use of picture exchange communication system (PECS). This involves pictures of items that the child wants, and they are taught to request that item, by selecting the appropriate picture card (Llaneza et al., 2010). This is a relatively inexpensive and simple system that facilitates communication for the child with ASD. Each child will have an individual book of pictures, unique to their needs, which creates a sense of familiarity for the patient (Llaneza et al., 2010). Preston and Carter (2009) published a review of the literature for the efficacy of the PECS system. They reviewed 27 studies, and found that there was some weak evidence that the PECS system was readily mastered by most children with ASD, and provided a useful means of communication for those with little or no discernible speech.

One parent/carer indicated that allowing the patient to look in a mirror, to pull faces might reduce the potential for negative behaviour. This is an interesting finding, as the literature suggests that the potential for self-representation is considerably reduced in children with ASD, compared with neurotypical controls (Carmody and Lewis, 2012). It may be that the visual stimulus of a face in the mirror would provide a distraction for the child, thereby reducing disruptive behaviour.

Distraction was suggested as a behaviour management technique by 7 parents/carers. Three of these parents/carers indirectly alluded to distraction, with the suggestion of, “stroking arms”, “massaging his forehead” and “stroking the palm of his hand in a circle”. A fourth parent/carer suggested the use of food as a distraction. The literature concurs with this finding. Marshall et al.

(2008) investigated the acceptability of various behaviour guidance techniques for children with ASD, from the point of view of their parents/carers. They surveyed 85 parents/carers, and found that 50% of parents/carers regarded distraction as an effective behaviour management technique for their children. Similarly, handholding by the parent was regarded to be effective by 70% of parents/carers. A number of parents/carers described the use of songs, games and a favourite toy as distraction mechanisms for their children. This is relevant to the dental practitioner, as games and toys in the waiting room may be beneficial for this group of children. This result was also fundamental in the development of the intervention for the ASD group in this study. The design of the smart phone application incorporated numerous games, such as a tooth brushing game, for children to play in the waiting room, or at home, if they have access to a smart phone, tablet device or computer.

The use of positive reinforcement was discussed by 2 parents/carers, with one parent/carer describing the use of verbal reinforcement and the other using the promise of a visit to McDonalds™ as a reinforcer. Positive reinforcement has long been an accepted form of behaviour management during the dental treatment of children. Skinner (1975) articulated the theoretical concepts of behaviourism, amongst them the notion of operant conditioning. Operant conditioning refers to a mechanism of learning whereby the individual's behaviour is modified by its consequences. This differs from classical conditioning in that operant conditioning deals with voluntary behaviour (Razran, 1955). Positive reinforcement is a form of operant conditioning, during which an individual acts on the environment to produce a consequence. Anything that the child regards as pleasant may be utilised as a reinforcer, such as verbal praise or a smiling face (Satwell et al., 1974)). This behaviour

guidance technique has been recommended for use for all paediatric dental patients, and there are no contraindications (AAPD, 2011).

Ferster (1961) first suggested the utilisation of positive reinforcement as a behaviour modification strategy for children with ASD. In this paper, he described the merits of both food and parental approval as effective positive reinforcers. This seminal paper acted as a catalyst for the development of comprehensive management protocols for children with ASD (Simpson, 1989). Marshall et al. (2008) found that 100% of parents of children with ASD listed positive reinforcement as an acceptable behaviour guidance tool for their children.

One parent/carer referred to the use of restraint as a behaviour management strategy. The British Society for Disability and Oral Health (2009), defines clinical holding as, “the use of physical holds (clinical holding), to assist or support a patient to receive clinical dental care or treatment, in situations where their behaviour may limit the ability of the dental team to effectively deliver treatment, or where the patient’s behaviour may present a safety risk to themselves, members of the dental team or other accompanying persons”. They acknowledge that clinical holding may be appropriate in cases where patients might lack the ability to comply with dental treatment, such as some patients with ASD. The literature supports a strong acceptance for the use of restraint as a behaviour management technique amongst parents/carers of children with ASD. Marshall et al. (2008) reported that almost 90% of parents/carers of children with ASD surveyed, considered restraint by the parent/carer during dental treatment acceptable, and 32% utilised this technique. Similarly, 60% of parents/carers reported acceptance of restraint by dental staff, with 30% reporting experience of this technique. It is important to

note that parents/carers were more accepting of restraint when they implemented it themselves. Loo et al. (2009) reported that protective stabilization involving dental staff, parents/carers or stabilization devices was the second most common advanced behaviour management technique utilised in a group of 395 children with ASD. It is noteworthy that 20% of the ASD group required protective stabilisation, but it was not necessary in the control group. Klein and Nowak (1999) reported a higher utilisation of restraint, by dental staff and parents/carers (almost 50%). This research involved the assessment of 43 case notes, and is therefore limited by its retrospective design in addition to a lack of a control group.

One parent/carer described tickling as a behaviour management mechanism. It is interesting to note that children with ASD have been shown to respond well to tickling by their parents. Reddy et al. (2002) reported that 100% of children with ASD were reported to laugh in response to tactile events such as tickling.

Relaxation was utilised as a behaviour guidance technique by 3 parents/carers, including the use of a quiet area, and encouraging the child to breathe deeply. The literature supports this suggestion. Rosenblatt et al. (2011) have demonstrated that relaxation induced through yoga significantly improved behaviour in children with ASD.

The use of Makaton™ as a behaviour management strategy was mentioned specifically in the comments section by one parent/carer. The Makaton™ vocabulary is a popular form of augmentative communication, consisting of a lexicon and symbols, accompanied by speech. The Makaton™ system should be considered as a stepping-stone to communication, rather than an independent communication method (Grove and Walker, 1990). This is an important finding, and it may be appropriate for dentists to familiarise

themselves with the Makaton™ sign for “finished”, in order to improve communication with children with ASD.

The notion of speaking to the child in a quiet, reassuring manner, the utilisation of a “*quiet area*”, and, “*removing him from what is upsetting him*”, were described as behaviour management strategies by 4 parents/carers in the study group. This may be due to hyperacusis in the ASD group, and this finding is consistent with published literature. Khalifa et al. (2004) investigated sound perception in a group of patients with ASD (N=11), compared with age and gender matched neurotypical controls. They reported that subjects with ASD demonstrated an increased loudness perception, in comparison to controls, and recommended that the acoustic environment be altered for patients with ASD, to improve quality of life for this group.

These comments by parents/carers, in the present study, provide useful information for the dental profession. It may be possible for the dental practice to reserve a quiet area or corner, without loud television, radio, or other children; for use by children with ASD should they wish to do so.

7.2.5 The Dental Surgery

It is significant that children with ASD were predicted by their parents/carers to demonstrate more negative behaviours within the dental surgery. This prediction is in accordance with a retrospective study by Loo et al. (2009), who reported that children with ASD showed significantly more uncooperative behaviour within the dental surgery than a neurotypical control group ($p < 0.001$). The researchers in this study did not differentiate between uncooperative behaviours, so it is difficult to make a direct comparison with the present study. Marshall et al. (2008) investigated parental perception regarding the potential

behaviour of a group of children with ASD, while undergoing a dental examination. They reported that 88% of parents of children with ASD predicted that their children would tolerate a dental examination. This differs from the present study, in that only 57% of parents/carers in the study group felt that their child would allow a dental examination. The reasons for this are unclear. It may be due in part to the older age range of the study group children in the Marshall et al. (2008) study. Parents/carers of children up to the age of 19 years were recruited, with 73% of children over the age of 7. In contrast, the study group of the present study included parents/carers of children between the ages of 3 and 16, with an average age of 9.82 years. Parents/carers may predict fewer episodes of negative behaviour in the older age group, although the authors do not address this issue.

Interestingly, children with ASD are perceived by their parents to show cooperative behaviour during medical examinations and interventions. Gillis et al. (2009) undertook a survey of 35 parents/carers of children with ASD. They enquired about their children's level of cooperation with various medical examinations and instruments. Procedures included; examining the heart, examining breathing, examining temperature, examining ears, examining throat and drawing blood. The instruments utilised included; a stethoscope, a sphygmomanometer, a thermometer, an otoscope and a knee reflex hammer. The modal response from parents/carers was "cooperative", for all examination procedures and associated instruments, apart from drawing blood, which resulted in a modal response of "uncooperative". This is in sharp contrast to the perceived uncooperative behaviour predicted by parents/carers in the current study.

The finding in this research that parents/carers of children with ASD are significantly less likely to wear protective glasses during the visit (59% versus 94.6% in the control group; p value <0.001), to lie back in the dental chair (57% versus 91% in the control group; p value <0.001), or to allow the experience of air/water in their mouths (34% versus 82% in the control group; $p < 0.001$) has not been previously reported in the literature. This information is beneficial for the dental practitioner, as it would allow the avoidance of protective glasses and the utilisation of the three in one syringe. It would also be possible to examine the patient in an upright position on the dental chair. These alterations to common practice might prevent the occurrence of negative behaviours within the dental surgery, and might potentially improve the dental experience for the patient with ASD, the dental team, and the parent/carer.

The finding that there was no difference in the proportions of children who were predicted to respond to being shown the dental equipment beforehand (73% versus 84%; $p = 0.167$) is to be expected. The tell-show-do technique is a commonly used technique within paediatric dentistry, and is highly recommended as a behaviour management technique for all children. (AAPD, 2011). It is a behaviour shaping technique, involving an age-appropriate explanation of the relevant technique, demonstration of the visual, auditory, tactile and olfactory properties of the technique and then completion of the procedure (AAPD, 2011). These results mirror those of Marshall et al. (2008). This group found that the tell-show-do technique was rated as an acceptable behaviour guidance technique for their children by 100% of parents/carers of children with ASD. In the same study, 77% of parents/carers rated the tell-show-do technique as being effective, when questioned following the dental visit.

Familiarity with the dental team was rated as highly beneficial by parents/carers in both the study group and the control group (95% versus 89% in the control group; $p = 0.297$). It is a well-established fact that patients with ASD show a preference for routine (Klin, 2006). The child with ASD may exhibit difficulty in accepting a change to routine, and become extremely distressed if this change is imposed upon them (Klin, 2006). It is not surprising that parents/carers in the control indicated that their children would be happier to be seen by the same dental team at each visit. The question “is your child happier to be seen by the same dentist and dental nurse on each visit? “ may have been too vague to establish a true difference between study and control group children, with respect to a need for routine, if one existed. The similarity between the two groups may not necessarily indicate a need for routine or sameness in control group children, but may be associated with a natural preference to continue to be seen by a familiar dental team. In this instance, parents/carers of the control group may have answered this question with respect to what their children would prefer, rather than whether a lack of familiarity with dental staff would represent a barrier to dental care for their children.

7.2.6 Dental Pain and Communication

The result that significantly fewer parents/carers in the study group would recognise if their children had dental pain (68% versus 98% in the control group; $p < 0.001$) mirrors previous findings in the literature. However, anecdotal evidence that patients with ASD have a higher pain threshold than neurotypical children has been refuted. Nader et al. (2004) examined the pain reactions of 21 children with ASD to a painful procedure (venepuncture), compared with a neurotypical control group. The objective measurement of pain was facial

expression. Parental perception of pain was also recorded. The study group displayed significant facial reactions to the procedure leading the authors to conclude that children in the study group did, indeed experience pain. However, there was little concordance between parental report and objectively measured pain. This research was limited by the technique of wrapping the children with ASD, but not the control group, in order to limit movement, in preparation for the procedure. Parents/carers in the current study endorsed this finding that parental reporting of pain may be inaccurate in the ASD group. This finding is contradicted, however, by the work of Bandstra et al. (2012). This research examined the capacity of a group of children and adolescents with ASD (n=20) to self-report pain, compared to parent-reported pain. This study questioned participants regarding the amount of pain they would expect to experience in several hypothetical situations. There was no difference in self-reported pain scores between the study and control group, nor was there a difference between self and parental pain scores in either group. This study is limited by the recruitment of high-functioning study group participants, which may not be representative of the entirety of the ASD spectrum.

The finding that a significantly lower number of children with ASD utilised speech as a method of communication (68% versus 100% in the control group;(p value <0.001) is well established in the literature. Children with ASD may have severe communication difficulties, with 20-30% failing to develop speech (Kiln, 2006). Parents frequently cite delays in the acquisition of verbal skills as an initial cause for concern (Klin, 2006). Given the lack of social responsiveness combined with language deficits in the ASD population, it is likely that abnormal pain expression may also be manifest (Nader et al., 2004).

This may in part account for the parental concern expressed, regarding the recognition of pain in study group children.

Although a significantly greater number of children in the ASD group did not use speech, 14.3% and 19.6% of these children were reported to utilise Makaton™ and PECS respectively. This is important information for the dental practitioner, prior to the dental visit. As previously mentioned, Makaton™ is a system designed to support spoken language, using signs and symbols to assist communication (Grove and Walker, 1990). PECS represents a communication system whereby the child exchanges a picture of symbol in exchange for a desired object (Liddle, 2001), and has been shown to increase the likelihood of speech development (Bondy and Frost, 2001). Both Makaton™ and the PECS system are augmentative communication aids, and are in frequent use by the ASD population (Mirenda 2001). As the Makaton™ and PECS communication systems are in popular usage by patients on the ASD spectrum, a basic knowledge of these systems may be useful for the dental team, to facilitate communication with this group of patients.

Ten percent of parents/carers indicated that their children did not communicate. The fact that patients with ASD have difficulty in both expressive and receptive communication is a well-established fact (Light et al., 1998). It is significant that almost one third of parents/carers within the study group reported that their children communicated by alternative methods (30.4%). These methods of communication can be broadly divided into the use of body language (pointing, guiding, making eye contact) and negative behaviour (making silly noises or gestures, inducing vomiting, screaming). The utilisation of body language may be a positive method of communication, which will potentially be easily understood by the dental team. However, communication, which is manifest as

negative behaviour may represent a barrier to dental care for this group of children. Communication difficulties may complicate dental treatment, and it is important that the dental team are aware of the potential for each patient to communicate, prior to their appointment.

7.2.7 Strategies for improving dental attendance

A significantly higher number of parents/carers in the study group indicated that the interventions proposed would be beneficial for their children. Photographs of the dental clinic prior to arrival were described as helpful by 62.5% in the study group versus 19.6% in the control group ($p < 0.001$). This reflects previous evidence that patients with ASD have a desire for consistency and sameness (Klin, 2006).

Similarly, a significantly higher proportion of parents/carers in the ASD group indicated that a social story™ prior to the dental visit would benefit their children (55.4% versus 17.9% in the control group; $p < 0.001$). As previously discussed, the social story™ is a well-accepted behaviour management technique, to inform the patient how to behave social situations (Quirnbach et al., 2009). A similar proportion of parents/carers in the ASD group indicated that a symbol strip would assist their child with the dental visit (55.4% versus 10.7%; $p < 0.001$). The potential use of symbol strips was suggested by parents/carers of children with ASD during the pilot study, and involves the production of a strip of PECS symbols associated with simple wording or phrases. This system has been demonstrated to increase language development in children with ASD (Ganz and Simpson, 2004).

Parents/carers in the study group indicated that allowing them to take photographs of their children within the dental clinic would be beneficial (58.9%

versus 7.1% in the control group; $p < 0.001$). This result again correlates well with the well-accepted preference of children with ASD for routine and sameness (Klin, 2006). It may be more beneficial for the child with ASD to see a photograph of themselves rather than a generic patient. The ability of patients with ASD to recognise images of themselves is established in the literature. Kita et al. (2011) demonstrated that patients with ASD perform as highly as controls in the area of self-face recognition.

The use of the Makaton™ sign for “finished” was considered to be potentially useful by a significantly higher proportion of the study group (41.1% versus 1.8% in the control group; $p < 0.001$). The utilisation of Makaton™ as a communication device is popular amongst patients with ASD, as previously discussed (Grove and Walker, 1990). The surprising aspect of this result is the fact that one parent/carer (1.8%) in the control group also indicated that this would be beneficial. The reasons for this are unknown. It may be that this parent/carer was unfamiliar with Makaton™ and ticked the box by mistake. It is also possible that this control group patient had a sibling, friend or relative who utilised Makaton™, and was therefore familiar with the signs involved.

There was a significant difference between study and control groups when questioned regarding the suitability of a domiciliary visit for their children ($p = 0.001$). Parents/carers did not elaborate on this point, but it may be that study group children who were unable to access dental care traditionally, may be more accepting of dental treatment within a familiar environment, such as their own homes, particularly if transport to the dental clinic represented a barrier to dental care for this group.

7.2.8 Frequency of Dental Visitation

There was a large variety in the recall schedules requested by parents/carers in both study and control groups. Overall, there was a significantly increased preference in the study group for three monthly reviews. This may be due to a desire to maintain a familiar routine in the ASD group, due to their documented preference for consistency (Klin, 2006). Parents/carers in the control group showed a significantly increased preference for a 6-monthly recall schedule. This may be due to the fact that the six-monthly dental examination has been customary in the past (Gibson and Moosajee, 2008), and parents/carers may have been trying to give what they thought was the correct answer. A higher number of parents/carers in the control group requested monthly appointments (3 versus 2 in the study group), but this difference was not significant. Similarly, an equal number of parents/carers in each group indicated that 2 monthly reviews would be appropriate for their children (n=1). There were a small number of preferences for an alternative recall schedule, including 4-monthly and yearly recalls. Overall, the vast majority of parents/carers requested either 3 or 6-monthly reviews. Knowledge that 3-monthly recall is preferred by the ASD group is useful for the dentist, as this may be arranged relatively easily for children with ASD.

7.2.9 Appointment Time

It is surprising that both study and control groups ranked the first appointment of the morning as the most desirable, as anecdotal evidence would suggest that the last appointment of the afternoon is the most frequently requested. This gives the advantage of allowing the child to complete the school day before attending the dental clinic. It may also facilitate parents/carers to leave work

early, rather than taking a half-day leave. Parents/carers did not specify the reasons for their preference. It may be that early morning appointments are convenient for the parents of the study group, as the child may be less tired, and therefore more likely to cooperate in the dental surgery. This preference may also reflect a worry about parking close to the dental surgery, as the car park is less likely to be busy at this time. The issue of waiting may also be involved, as the first appointment of the morning will almost guarantee immediate access to the dental surgery. Parents/carers may also feel that the waiting room is less likely to be busy at this time, providing a quiet environment for the child.

7.2.10 Any other thoughts or ideas about difficulties your child may experience while visiting the dentist?

Parents/carers in the study group utilised this section to reiterate their previous recommendations, with little novel information added at this point. The benefits of the Applied Behaviour Analysis (ABA) programme were reinforced. Parents/carers repeated the importance of having a quiet waiting area for their children, and of minimal waiting times. Acclimatisation to the dental experience and the introduction of distraction techniques were discussed. Parents/carers described the advantage of short, direct verbal communication, in association with verbal communication with their children. The sounds and smells of the dental clinic were described as potential barriers to dental care. Short, frequent appointments were favoured. Parents/carers again quoted a lack of dentists with the specialist skills required to understand and treat their children as a significant barrier to their dental care. This mirrors previously published research in an American population. Brickhouse et al. (2008) reported that the

inability to find a dentist with the necessary skills and willingness to treat children with ASD.

Parents/carers noted that time off work to attend dental appointments would potentially be problematic for them. This is a noted barrier to dental care for children with for children with disabilities. Al Agili et al. (2004) investigated the barriers to dental care for children with disabilities and found that 7.5% of parents had difficulty in securing time off work to attend the appointment. This study did not include children with ASD, but the results may be generalisable to this group.

The only novel information yielded by this section of the questionnaire was the recommendation, by a number of parents/carers in the study group that their children would require a general anaesthetic (GA) for dental treatment. This is in accordance with published literature. Marshall et al. (2008) reported that 95% of parents of children with ASD ranked the use of GA as an acceptable behaviour guidance technique, and 55% felt that it would be effective for their children. Loo et al. (2009) investigated the usage of GA for the dental treatment of children with ASD in Boston, USA. They reported that GA was the most commonly utilised behaviour guidance technique in this group (37%). A significantly higher proportion of the ASD group underwent GA for dental treatment, when compared to healthy, neurotypical controls. The acceptance of GA by parents in both of these studies may have been influenced by their medical insurance status. If they were un-insured or under-insured, they may not have been able to afford a GA, rather than not accepting it as a behaviour management technique. The American Academy of Paediatric Dentistry endorses this finding, in the guideline on management of dental patients with special healthcare needs. They recommend GA as the behaviour guidance of

choice, if all other options in the behaviour armamentarium are untenable (AAPD, 2008). This present research demonstrates an acceptance by parents/carers within a UK population for GA as a behaviour management technique for their children.

Within the control group, a number of parents/carers described needle phobia as a potential barrier to dental care for their children. This may be, in part due to the method of recruitment to the control group. As previously stated, the control group was recruited from parents/carers of children who had been referred to a specialist dental service, and therefore may exhibit higher levels of dental anxiety than the general population. One parent/carer in the control group requested that the dentist directly address the child, rather than the parent, and all dental procedures were to be explained, which may be a personal preference, and may not be representative of the control group as a whole. Reassuringly, a number of parents/carers in the control group reported that their children were happy to attend the dentist.

7.2.11 Limitations of the study

This research was limited in a number of ways. In the first instance, the questionnaire utilised to collect data was of a novel design, and may not have been comprehensive. In an effort to reduce this limitation, the questionnaire was piloted prior to use, with a focus group comprising of parents/carers of children with ASD. The questionnaire was discussed with this group, and any recommended alterations to the design were implemented. This ensured that all pertinent data, within reason, was included. This pilot study informed the final study design.

This research was powered, by a statistician, to investigate barriers to dental care for children with ASD. The numbers recruited were insufficient to allow sub-group analysis by age, to assess the effect, if any, of increasing age on barriers to dental care for this group of children. However, this was not the research question, and may be dealt with more appropriately in further research on this topic.

Parents/carers who didn't speak English were excluded from this study. This may have limited the results, by excluding some potential participants. However, a lack of spoken English may, in itself represent a barrier to dental care. Therefore, the inclusion of this group may have potentially introduced confounders into the study.

This research may have been limited by the nature of the identification of potential barriers to dental care for children with ASD. Barriers recorded were those perceived by parents/carers, and may not be representative of actual barriers to dental care. However, it is likely that parents/carers based many of their perceptions on past behaviour, which would have rendered them more accurate. The completion of the questionnaire may also have been subject to recall bias, with past episodes of negative behaviour being more memorable for parents. It may also be that parents/carers overestimated their children's behaviour, particularly if they experienced some dental anxiety themselves. The literature suggests that parents/carers can accurately predict their children's behaviour at a first dental appointment. Pfefferle et al. (1982) investigated parental prediction of the behaviour of 48 children (36-60 months) prior to their first dental visit. They found that parents were able to accurately predict behaviour, both positive and negative at the first dental visit. Whether this result can be extrapolated to children with ASD is uncertain. Marshall et al.

(2008) investigated parental ability to predict cooperative behaviour at dental appointments, for a group of children with ASD. They reported that parents were able to accurately predict behaviour during dental examination, and relatively accurately predict behaviour during the exposure of bitewing radiographs. They performed less well when predicting behaviour during dental prophylaxis and the application of fluoride varnish. Overall, parents were shown to be accurate predictors of behaviour, both at initial and return visits, and by procedure. Another outcome of this study was that parents tended to overestimate the cooperation of the ASD group.

Whether parents/carers can be seen to accurately predict the behaviour of their children is unclear. Nevertheless, if a problem is perceived to exist for this group, by their parents/carers, then it is justified to assume that a problem does exist.

The study group for this research was recruited from two sources. Firstly, from parents/carers of children with ASD who were already accessing the dental services in the Hull and East Riding area. Secondly, from parents/carers of children with ASD, attending special schools in the Hull and East riding area. As parents/carers recruited from through the dental services were, by definition already accessing dental services, it is logical to assume that, if barriers existed to dental care for their children, that they had already overcome them. In an effort to recruit parents/carers of children with ASD who were unable to access dental services, recruitment was extended to special schools in the area. A high proportion of respondents from special schools reported that they accessed dental care for their children. It may be that there was some participation bias – those parents who were interested in accessing dental services for their children were more likely to return the questionnaire. Given

that there was no difference in dental attendance between the study and control groups, it may be that this sample was not truly representative of the ASD population. It may also imply that parents/carers in the Hull and East Riding area are proactive in overcoming barriers to dental care for their children.

The study and control group children were age and gender matched. Residential area was used as a proxy for socioeconomic status. This may not have been an accurate mechanism of matching for socioeconomic status as it assumes population homogeneity within that postcode. There are a number of methods of socioeconomic status matching. The Townsend Index of Disadvantage and Deprivation uses a number of variables to assign an overall deprivation score to each area in the UK (Dolan et al., 1995). The Carstairs deprivation score is similar to the Townsend index, and both mainly measure material deprivation (Dolan et al., 1995). The Jarman index, and the UK Indices of Multiple deprivation (IMD) will also measure deprivation. Researchers commonly divide geographical areas into quintiles, based on these indices. They are commonly used to analyse variations in health between affluent and deprived areas (Weightman et al., 2012).

Matching for socioeconomic status was important in this study, as barriers to dental care were examined. Transport barriers, such as not owning a car may be increased in the lower socioeconomic status group, and would have represented a confounding factor if study and control group participants were not matched. There is also evidence in the literature that dental anxiety is associated with low income (Doerr et al., 1998).

Matching of study and control groups by age was successful. This was important, as barriers to dental care in neurotypical children have been shown to decrease with age, while those of children with ASD may not. Loo et al.

(2009) demonstrated that there was no significant difference in the proportions of children with ASD and neurotypical children under the age of 11 years, who required a GA for dental treatment. This was because the majority of children in the neurotypical group were pre-cooperative. A significantly higher proportion of the ASD group required a GA for dental treatment in the 11-18 years group, and the above 18 years group.

The control group was recruited from parents/carers of healthy, neurotypical children, attending a consultant-led specialist dental service. This group of children had been referred to a specialist service for a range of different reasons, including behaviour management. It may be that this group demonstrated a high level of perceived barriers to dental care, and as such, may not have been representative of the general population. Although significant differences were noted between the study and control groups, this difference may have been more striking if the control group had been selected for parents/carers of children attending general dental practitioners for dental treatment.

The response rate for this study was 56%. This was a relatively high response rate, as the literature shows that poor response rates are a particular problem associated with questionnaire studies (Williams, 2003). It has been shown in the literature that people are more likely to respond to a questionnaire if the questions are salient to the respondent (Heberlein and Baumgartner, 1978). To this end, the focus group facilitated the identification of relevant issues for the ASD population. It also promoted the identification of new issues, through the interaction of participants. The potential range of answers for each question was clarified at this focus group.

Thirty-six of the parents/carers were recruited from those attending the dental service, and mostly elected to complete the questionnaire in the waiting room (72% response rate). This was advantageous, as it enabled the primary investigator to clarify any ambiguous questions, and also to ensure that all sections of the questionnaire were completed. The benefits of this were balanced against the disadvantage of potentially disrupting busy clinics. The completion of the questionnaire in the waiting room may have promoted a feeling of intimidation, with respondents altering their responses to please the researcher. Fifty questionnaires were sent to special schools, with a response rate of 40% (20 questionnaires). The disadvantage of this method of recruitment was the lack of control over who completed the questionnaire. It may be that some of the parents/carers of children attending the Special Schools did not respond, as they were had already completed a questionnaire at the dental clinic.

Test-retest was not undertaken, as it was deemed to be overly onerous for parents/carers of children with ASD to dedicate additional time to the completion of a second questionnaire. Therefore, the reliability of the questionnaire was not demonstrated.

As this research was completed within the Hull and East Riding area, the results are specific to this group of patients, and may not be generalisable to the United Kingdom as a whole.

8.0 Intervention

An intervention package, consisting of a pre-appointment questionnaire (Appendix 9) was developed in the first instance. This is now posted to all parents/carers of children with ASD prior to the dental visit, to enable the dentist to have prior knowledge of each individual patient's preferences regarding noise, bright lights and waiting in the waiting room. Prior information about a particular patient's preferences regarding light, sound and touch will allow avoidance of any potentially distressing experiences for both the patient and parent/carer. The questionnaire will also identify potential trigger factors for negative behaviour in these patients, and give some prior warning of predicted negative behaviour, which may signify a child's poor tolerance of the dental procedure. Photographs of the dental clinic and staff are included with this questionnaire, and will allow patients to familiarise themselves with the dental experience. A social story™ was also produced, in association with these photographs and this is routinely included with the intervention questionnaire, explaining all the steps involved in visiting the dental clinic, and giving the patient information on how they should behave in each social situation. A parking space has been reserved, close to the door of the dental clinic, for parents/carers of children with ASD. If a particular parent has had difficulty with waiting in the waiting room, we will organise an appointment at a quiet time – perhaps last thing in the afternoon, when the clinic will be less busy.

The production of an application for smart phones and tablet devices has taken into account the parental preference for the idea of pre-appointment photographs of the dental clinic, the idea of a social story™ and the concept of familiarity with the dental team. The application embraces the current popularity of android™ and Apple iPhones™ in addition to tablet devices such as the

Apple iPad™. Published literature has suggested that children with ASD benefit from the use of the Apple iPad™ to establish and develop their communication skills (Flores et al., 2012). This research compared the development of social and communication abilities in children with ASD. These children had an established history of picture card utilisation. Employment of the Apple iPad™ to augment communication was shown to be beneficial in a number of cases, and equivalent in others. This research was limited in its conclusions however, by a small sample size (n=5). These results imply the need for further exploration of this contemporary technology and its possible benefits for children with ASD.

The notion of an application detailing the dental visit is not novel. There are some available applications for the ASD population, describing the dental experience (Webster, 2008). This application demonstrates a visit to a generic dental practice, illustrated in cartoon form. The development of an application that is specific to our dental clinic has not been, to our knowledge, previously reported in the literature. The application will allow the patient to take a virtual tour of the dental clinic, prior to arrival. The front door to the clinic at Highlands Dental Clinic makes a characteristic sound on opening, and this has been incorporated into the application, to aid the authenticity of the virtual tour. The photographs of the dental clinic have been converted to a cartoon style, in an effort to more closely resemble a game and to make the application more attractive to children. Representative stills from this application are included in appendices (appendices 13-17). The inclusion of sound effects, including the original voices and accents of the dental staff, will allow the patient to become familiar with the dental experience. The application will allow the patient to hear the sounds of the dental surgery, including the fast and slow handpieces, and

there are some in-built games, for example a tooth-brushing game for patients to play.

Details of this application will be included with the pre-appointment questionnaire for parents/carers of children with ASD as soon as it becomes available on the Apple™ and Android stores. It is envisaged that this application will be available free of charge for all parents who possess a smart phone or tablet device. In the interest of equity, the application will also be available on the City Healthcare Partnership (CHCP) Hull website, and details of this will be included with the pre-appointment questionnaire. An Apple iPad has been purchased, through the funding for this research, from the University of Leeds. The dental application will be downloaded to this iPad™. It will be permanently stored at Highlands Clinic, Hull, and will be available in the waiting room for utilisation by children with ASD. This may serve as a distraction in addition to enhancing communication with the patient, and it is hoped that the availability of this iPad™ will help to improve the dental experience for children with ASD and their parents.

10.0 Null Hypothesis Rejection

As a result of this research, the null hypothesis that “there are no barriers for children with autism spectrum disorder in accessing dental care in the Hull and East Riding area” can be rejected.

11.0 Further Research

This research was affected by a number of limitations as previously outlined. Further investigation, involving the recruitment of larger numbers of participants would allow sub group analysis according to age. This would determine whether barriers to dental care are age determined, for children with ASD. Future work is recommended in the area of the investigation of the effectiveness of the intervention. Initially, this intervention could be assessed by producing a feedback form, for parents/carers of children with ASD who had experienced the intervention. If this were to be proven to be successful, the intervention could then be rolled out to a larger number of dental surgeries within the Hull and East Riding area.

12.0 Conclusion

The results of this research has given us an insight into the barriers to dental care experienced by children with ASD and their parents/carers in the Hull and East Riding area. There is little published research identifying barriers to dental care in this population, and no data to date on the particular barriers to dental care experienced by children with ASD in the United Kingdom (UK). From the results of this research, it can be concluded that:

1. Difficulties exist for children with autism spectrum disorder in accessing dental care in the Hull and East Riding area
2. A strategy was developed to potentially help to improve this access to dental care for children with autism spectrum disorder

These results have provided much needed clarification of this important issue, and have been instrumental in developing an intervention to potentially help to improve access to dental services for these patients. The development of a questionnaire, specifically enquiring about the most common barriers to dental care experienced by children with ASD in the Hull and East Riding area provided their parents/carers with a means to communicate some of their expectations and fears regarding the upcoming dental visit. It was beneficial both to the dental team, and to the patient/parent/carer for information to be available in advance of any potential issues that may arise during the visit. This research had the unique advantage of identifying potential barriers to dental care experienced by the child with ASD from the perspective of parents/carers. This has allowed a greater understanding of the potential issues that may be faced by this diverse group. It is hoped that the results of this study have helped to alleviate those issues, and improved the dental experience for this vulnerable group and their parents/carers.

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Appendices

		Page
Appendix 1	Introductory Letter to Focus Group	XXI
Appendix 2	Study Group Information Sheet	XXII
Appendix 3	Questionnaire	XXV
Appendix 4	Consent Form	XXXIII
Appendix 5	Control Group Information Sheet	XXXIV
Appendix 6	DREC Approval	XXXVII
Appendix 7	NRES Approval	XXXVIII
Appendix 8	NRES Progress Report	XLIII
Appendix 9	REC Approval	XLIV
Appendix 10	Intervention Questionnaire	XLV
Appendix 11	Social Story	LII
Appendix 12	Front Door of Highlands Dental Clinic, Hull	LIV
Appendix 13	Waiting Room in Highlands Dental Clinic, Hull	LV
Appendix 14	Reception Desk in Highlands Dental Clinic, Hull	LVI
Appendix 15	Corridor to Dental Surgery, Highlands Dental Clinic, Hull	LVII
Appendix 16	Dental Surgery, Highlands Dental Clinic, Hull	LVIII

Appendix 1

Leeds Dental Institute

The Centre for Oral Health Sciences



Title: Improving Access and Reducing Barriers to Care for Children with Autistic Spectrum Disorder

My name is Siobhán Barry, and I am a Specialist Registrar in Paediatric Dentistry. I am based at the Leeds Dental Institute, and Highlands Dental Clinic, North Bransholme, Hull.

I am undertaking a doctorate degree, through the University of Leeds, and aim to establish the barriers to dental care for children with Autistic Spectrum Disorder in the Hull and East Riding area. In order to do this, I need to first develop a suitable questionnaire to distribute to parents of children with Autistic Spectrum Disorder.

I would be grateful if you could take a short time to chat with me, and let me know what you consider to be the barriers to dental care experienced by children with Autistic Spectrum Disorder.

If you need any further information regarding this research, please contact:

Professor KJ Toumba,
Professor of Paediatric Dentistry,
Department of Paediatric Dentistry,
Leeds Dental Institute,
Worsley Building,
Clarendon Way,
Leeds.
LS2 9NL.
Phone: 0113 3436141
E-mail: K.J.Toumba@leeds.ac.uk

Appendix 2



Leeds Dental Institute

The Centre for Oral Health Sciences

Department of Paediatric Dentistry
A Centre for Children with Special Needs

Level 6, Worsley Building
Clarendon Way, Leeds, LS2 9LU
Tel: Enquiries +44 (0) 113 343 6138
Fax: +44 (0) 113 343 6140
Email: dnsmb@leeds.ac.uk

Study Title: Improving Access and Reducing Barriers to Dental Care for Children with Autistic Spectrum Disorder (ASD)

Researcher: Dr Siobhán Barry

Study information sheet (Parent of study group):

Dear Parent or Guardian

You and your child are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aims of the study are;

1. To examine the problems encountered by children with ASD when accessing dental care, in the Hull and East Riding area.
2. To develop a plan to improve this access to dental care

Why have I been chosen?

It is thought that children with autism spectrum disorder experience problems in accessing dental care. Among these difficulties are problems with transport to the dental clinic and problems with cooperation for dental care. Your child has autistic spectrum disorder, and we would like to obtain information on any barriers to dental care that they experience.

What will the study involve?

The study will involve filling out a short questionnaire. We will compare your answers to those of parents/guardians of children without autism spectrum disorder. We can then identify whether there are specific barriers to care that affect patients with ASD. Following this, we will try to help patients with ASD and their families to overcome these problems.

Do I have to take part?

Participation in this study is entirely voluntary. If you do decide to take part you will be asked to sign a consent form, and to fill in a questionnaire. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your child receives.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks.

Will I benefit from taking part?

Your child may or may not benefit directly from the study. Information obtained during the course of the study may help us to gain a better understanding of the difficulties experienced by patients with autism spectrum disorder, when accessing dental care. We hope that by knowing more about these difficulties, we will be able to develop ways to help these patients and their families.

Will my taking part in this study be kept confidential?

If you and your child consent to take part in this study, you will be identified only by number. No personal identifiable information will be kept, so you or your child cannot be identified.

What will happen to the results of the research study?

We will report on the results as a research thesis for a higher degree. You or your child will not be identified by name in any reports that we write.

Who is organizing and funding the research?

The study is being carried out by a Specialist Registrar in Paediatric Dentistry, as part of a Clinical Doctorate Degree in Paediatric Dentistry. It will be carried out in Highlands dental clinic, Hull, and the Leeds Dental Institute. A consultant in Paediatric Dentistry and a Professor of Paediatric Dentistry are supervising the study.

Who has reviewed the study?

Both the local research ethics committee and the national research ethics committee have reviewed the study.

Contact for further information

If you would like any further information please do contact us

Dr Siobhán Barry 01482 303600 dnsmb@leeds.ac.uk

Dr Elizabeth O'Sullivan 01482 303600 elizabeth.o'sullivan@chcphull.nhs.uk

Professor KJ Toumba 0113 3436138 K.J.Toumba@leeds.ac.uk

Thank you for reading this information sheet. Please keep this and a copy of the consent form for your records.

Appendix 3

Leeds Dental Institute



Hull

The Centre for Oral Health Sciences

Title: Improving access and reducing barriers to dental care for children with Autistic Spectrum Disorder

Researcher: Dr Siobhán Barry

ID Number:

1. Does your child attend dental services?

Yes No

2. If no, please describe the reasons why in the space provided:

3. If yes, have you experienced difficulty in accessing this dental service?

Yes No

4. If you have experienced difficulties, please describe them in the space provided:

5. Does your child experience difficulty when travelling to the dentist by car?

Yes No

6. Does your child experience difficulty when travelling to the dentist by public transport?

Yes No

7. Do you feel that you would need to park close to the door of the clinic when attending with your child for a dental visit?

Yes No

8. Would it be difficult for your child to wait in the dental waiting room?

Yes No

9. Would it make a difference for your child if the dental waiting room were busy?

Yes No

10. Would it be helpful if you could phone the dental clinic just before arrival, to allow your child to come straight into the dental surgery, rather than the waiting room?

Yes No

11. Please rank the following appointment times in order, from the most suitable time for your child to attend the dentist, to the least suitable time for your child to attend the dentist: 1=most suitable, 5=least suitable

- First thing in the morning
- Mid morning
- First thing after lunch
- Mid afternoon
- Last thing in the afternoon

12. Is your child's behaviour liable to change suddenly?

Yes

No

13. If yes, is this behaviour change associated with any of the following triggers? (Please include all that are appropriate and rank in order from the trigger most likely to alter your child's behaviour to the trigger least likely to alter your child's behaviour): 1=most likely to be a trigger, 9=least likely to be a trigger

- No reason
- Bright lights
- Loud noise
- Having his/her head touched
- Strange tastes
- Strange smells
- Enclosed spaces
- Dental gloves
- Dental mask

14. If yes, please indicate which of the following behaviours your child may display (please tick all that are appropriate):

- Crying
- Self-harming
- Head butting
- Biting
- Spitting
- Laying on the floor
- Hitting/lashing out
- Positive behaviour

15. Do you have any specific behaviour management techniques that you use with your child, such as counting to ten or stop signals?

Yes No

16. If yes, please describe these technique/s in the space provided:

17. Is your child happy to wear protective glasses?

Yes No

18. Is your child happy to lie back on the dental chair?

Yes No

19. Is your child happy to have his/her mouth examined?

Yes No

20. Is your child happy to accept air/water in his/her mouth?

Yes No

21. Would your child be happier if we showed him/her the dental equipment beforehand?

Yes No

22. Is your child happier to be seen by the same dentist and dental nurse on each visit?

Yes No

23. Do you know when your child is in dental pain?

Yes No

24. How does your child communicate? Please indicate all appropriate answers:

- Speech
- Makaton
- Picture Exchange Communication System (PECS)?
- Does not communicate
- Other _____

25. Which, if any of the above means of communication does your child use most often?

26. Would it be helpful to have some photographs of the dental clinic and staff for your child to see before his/her dental visit?

Yes No

27. Would it be helpful to have a social story about the dental visit included with your child's initial appointment?

Yes No

28. Would it be helpful to have a symbol strip about the dental visit included with your child's appointment?

Yes No

29. Would it be helpful for you to take a photograph of your child in the dental waiting room or dental chair?

Yes No

30. Would it be helpful if the dentist could sign, "finished", in Makaton when treatment is complete?

Yes No

31. If your child refuses to attend the dentist, would it be helpful to organise a domiciliary visit?

Yes No N/A

32. How frequently do you think your child will need to visit the dentist, once a relationship has been established? (If other, please indicate the appropriate frequency in the space provided)

- Monthly
- Every 2 months
- Every three months
- Every six months
- Other _____

33. Do you have any other thoughts or ideas about difficulties your child may experience while visiting the dentist?

Thank you for your help

Appendix 4



Leeds Dental Institute

The Centre for Oral Health Sciences

Title: Improving access and reducing barriers to dental care for children with Autistic Spectrum Disorder

Researcher: Dr Siobhán Barry

Consent form

Please initial the box on the right hand side of the sheet to indicate that you agree with the statements.

1. I have read and understood the information sheet for the above study. I have had the opportunity to consider the information and ask questions and have had these answered satisfactorily.
2. I understand that participation is voluntary and that I am free to withdraw my child at any time without giving reason and without affecting my child's future care.
3. I agree to take part in the study.

Signature of parent
Name (block capitals)

Date

Signature of child (if over 12 years of age)
Name (block capitals)
(Optional)

Date

Signature of researcher
Name (block capitals)

Date

Appendix 5

Leeds Dental Institute The Centre for Oral Health Sciences



Department of Paediatric Dentistry
A Centre for Children with Special Needs

Level 6, Worsley Building
Clarendon Way, Leeds, LS2 9LU
Tel: Enquiries +44 (0) 113 343 6138
Fax: +44 (0) 113 343 6140
Email: dnsmb@leeds.ac.uk

Study Title: Improving Access and Reducing Barriers to Dental Care for Children with Autistic Spectrum Disorder (ASD)

Researcher: Dr Siobhán Barry

Study information sheet (Parent of control group):

Dear Parent or Guardian

You and your child are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aims of the study are;

1. To examine the problems encountered by children with ASD when accessing dental care, in the Hull and East Riding area.
2. To develop a plan to improve this access to dental care

Why have I been chosen?

It is thought that children with autism spectrum disorder experience problems in accessing dental care. Among these difficulties are problems with transport to the dental clinic and problems with cooperation for dental care. Your child does not have ASD. However we would like to involve children without ASD in our study so that we can compare them to children with ASD.

What will the study involve?

The study will involve filling out a short questionnaire. We will compare your answers to those of parents/guardians of children with autism spectrum disorder. We can then try to identify whether there are specific barriers to care that affect patients with ASD. Following this, we will try to help patients with ASD and their families to overcome these problems.

Do I have to take part?

Participation in this study is entirely voluntary. If you do decide to take part you will be asked to sign a consent form, and to fill in a questionnaire. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your child receives.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks.

Will I benefit from taking part?

It is unlikely that your child will benefit directly from the study. However, information obtained during the course of the study may help us to gain a better understanding of the difficulties experienced by patients with autism spectrum disorder, when accessing dental care. We hope that by knowing more about these difficulties, we will be able to develop ways to help them.

Will my taking part in this study be kept confidential?

If you and your child consent to take part in this study, you will be identified only by number. No personal identifiable information will be kept, so you or your child cannot be identified.

What will happen to the results of the research study?

We will report on the results as a research thesis for a higher degree. You or your child will not be identified by name in any reports that we write.

Who is organizing and funding the research?

The study is being carried out by a Specialist Registrar in Paediatric Dentistry, as part of a Clinical Doctorate degree in Paediatric Dentistry. It will be carried out in Highlands dental clinic, Hull, and the Leeds Dental Institute. The study is being supervised by a Consultant in Paediatric Dentistry and a Professor of Paediatric Dentistry.

Who has reviewed the study?

Both the local research ethics committee, and the national research ethics committee have reviewed the study.

Contact for further information

If you would like any further information please do contact us

Dr Siobhán Barry 01482 303600 dnsmb@leeds.ac.uk

Dr Elizabeth O’Sullivan 01482 303600 elizabeth.o’sullivan@chcphull.nhs.uk

Professor KJ Toumba 0113 3436138 K.J.Toumba@leeds.ac.uk

Thank you for reading this information sheet. Please keep this and a copy of the consent form for your records.

Appendix 6

Quoting Julie McDermott <J.K.McDermott@leeds.ac.uk>:

Dear Siobhan,

Thank you for submitting your amended documents for the above Ethics application. I confirm that DREC has re-reviewed your application and are happy for you to proceed and apply for full NHS Research Ethics Committee approval, subject to the following recommendations:

REC form -It is suggested that the Highlands Dental Clinic is added as a research site under 'Section C' of the REC form. It is also advisable that an additional SSI form for R&D approval is sent to the local PCT in East Riding as well as to the Leeds Teaching Hospitals Trust. The address and contact information can be found on the R&D Forum website at: www.rdforum.nhs.uk<<http://www.rdforum.nhs.uk>>-A72: Amend no of NHS organisations to 2 and total UK sites in study to 3

If you need any further information, please do not hesitate to contact me.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, signed consent forms, participant information sheets and all other documents relating to the study. This should be kept in your study file, and may be subject to an audit inspection. If your project is to be audited, you will be given at least 2 weeks' notice.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

With best wishes for the success of your project.

For and on behalf of Professor Gail Douglas
DREC Chairman

Appendix 7



National Research Ethics Service

NRES Committee North East - Newcastle & North Tyneside 2

Room 002
TEDCO Business Centre
Rolling Mill Road
Jarrow
NE32 4BW

Telephone: 0191 428 3565
Facsimile: 0191 428 3432

27 May 2011

Dr Siobhan Barry
Specialist Registrar in Paediatric Dentistry
Department of Paediatric Dentistry
Leeds Dental Institute
Worsley Building
Clarendon Way
Leeds
LS2 9LU

Dear Dr Barry

Study title: Improving Access and Reducing Barriers to Care for
Children with Autistic Spectrum Disorder
REC reference: 11/NE/0142

The Proportionate Review Sub-committee of the NRES Committee North East - Newcastle & North Tyneside 2 Research Ethics Committee reviewed the above application on 27 May 2011.

Ethical opinion

This application was considered to be well written and the sensitivities regarding the initial approach and consent recognised and dealt with appropriately.

The following issues were raised by the sub-committee and as chief investigator you responded accordingly as follows.

1. It was noted that the parents might be upset or distressed and this will be dealt with by explanation of the proposed outcomes in the information sheet. Despite the explanation on the sheet there may be participants who are distressed as they remember a previous incident and wish to talk about it. Clarification was requested regarding strategies in place should the investigator be contacted by someone who is distressed and is looking for support with their distress in a practical sense.

You explained that all parents/carers involved in the research will have access to the Paediatric Dental Team, who can help them with any distress/worries, and who can refer them to the relevant service for advice and help. There is a parent support group for parents/carers of children with ASD in Hull, who can be contacted via the researchers. There is also access to the psychology department in the Leeds General Infirmary for advice/help. In addition to this, parents/carers who may be distressed can also be directed to the patient/advice and liaison service (PALS) if necessary.

2. Non-English speakers will be excluded and the use of interpreters ruled out due to the cost implications. It was queried if this is a significant group in this patient population and if non-English speakers will have a distinct access problem. Also it was queried how this issue will be dealt with when writing up the results.

You informed that there are likely to be few, if any, non-English speakers in the Hull area, and a high number of non-English speaking potential study participants is not anticipated. Therefore, this would not affect or bias the results. Including non-English speakers may, however, introduce a confounder into the study, as not speaking English may be a barrier in itself. This barrier to dental care is unrelated to the research question. This issue will be discussed fully in the write up

Decision

On behalf of the Committee, the sub-committee gave a **Favourable** ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised

documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	S Barry	12 May 2011
REC application	(IRAS v 3.1)	21 April 2011
Evidence of insurance or indemnity	Zurich Municipal	29 September 2010
Other: CV for academic supervisor E Sullivan		09 May 2011
Participant Consent Form	v 2	20 May 2011
Participant Information Sheet: Parent of Control Group	v 2	20 May 2011
Participant Information Sheet: Parent of Study Group	v 2	20 May 2011
Protocol	v 2	23 February 2011
Questionnaire: Non-Validated		01 December 2010
Referees or other scientific critique report	E O'Sullivan - Academic Supervisor	19 May 2011

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

11/NE/0142

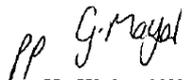
4

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/NE/0142	Please quote this number on all correspondence
------------	--

With the Committee's best wishes for the success of this project

Yours sincerely



Mr Michael Wyatt
Vice Chair

Email: gillian.mayer@sotw.nhs.uk

Enclosures: List of names and professions of members who took part in the review
"After ethical review – guidance for researchers" SL-AR2

Copy to: Ms Rachel De Souza - Faculty Research Office, Room 10.110,
University of Leeds, Clarendon Way, Leeds LS2 9NL

NRES Committee North East - Newcastle & North Tyneside 2**Attendance at PRS Sub-Committee of the REC meeting on 27 May 2011****Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Rev Nigel M Goodfellow	Head of Chaplaincy	Yes	
Dr Sumaira MacDonald	Consultant Vascular Radiologist/Honorary Clinical Senior Lecturer	Yes	
Mr Michael Wyatt (<i>Vice Chair</i>)	Consultant General and Vascular Surgeon	Yes	

Appendix 8



Health Research Authority

NRES Committee North East - Newcastle & North Tyneside 2

Room 002
TEDCO Business Centre
Rolling Mill Road
Jarrow
NE32 4BW

Tel: 0191 428 3565
Fax: 0191 428 3432

11 July 2012

Dr Siobhan Barry
Specialist Registrar in Paediatric Dentistry
Department of Paediatric Dentistry
Leeds Dental Institute
Worsley Building
Clarendon Way
Leeds LS2 9LU

Dear Dr Barry

Study title: Improving Access and Reducing Barriers to Care for
Children with Autistic Spectrum Disorder
REC reference: 11/NE/0142

Thank you for sending the progress report for the above study dated 17 June 2012. The report will be reviewed by the Chair of the Research Ethics Committee, and I will let you know if any further information is requested.

The favourable ethical opinion for the study continues to apply for the duration of the research as described in the application and protocol agreed by the REC, taking account of any substantial amendments.

11/NE/0142:	Please quote this number on all correspondence
--------------------	---

Yours sincerely

Gillian Mayer
Committee Co-ordinator

E-mail: gillian.mayer@sotw.nhs.uk

Copy to: Ms Rachel De Souza – Faculty Research Office, Room 10.110, University of Leeds, Clarendon Way, Leeds LS2 9NL

Ms Caroline Mozley - North Yorkshire Alliance R&D Unit, Learning & Research Centre, York Hospital, York YO31 8HE

Appendix 9

Elizabeth

Considering the delay in this process and current position with York I will grant approval for this study. My upmost apologies for the undue concern that this has generated and round the houses attempts you and Siobhan have had to go through to get to this stage. I hope the research is a success.

Regards

Andrew

Andrew Burnell

Chief Executive

Appendix 10



Leeds Dental Institute

The Centre for Oral Health Sciences

Pre- Appointment Questionnaire for parents/carers of children with Autism Spectrum Disorder

Researcher: Dr Siobhán Barry

Highlands dental Clinic,
Lothian Way,
North Bransholme,
Kingston Upon Hull,
HU7 5DD
01482 303620

Dear Parent/Carer,

We at Highlands Dental Clinic are currently involved in research in Autism Spectrum Disorder (ASD), in an effort to improve the care we provide for children with this condition. We would be greatly obliged if you would consider completing this questionnaire, which would hopefully assist us in addressing the individual needs of your child.

This questionnaire should take no longer than 10 minutes to complete, and we hope that it will lead to a better dental experience for you and your child.

Ideally we would like if you could return this questionnaire by post, prior to your child's visit, as it would allow us to plan the visit. Otherwise, please bring it with you on the day of your appointment.

A parking space has been reserved, close to the door of the dental clinic, for parents/carers of children with ASD, to facilitate easy access to the clinic.

If you feel that phoning prior to your child's arrival at the clinic, to allow you to avoid the waiting room, and immediately enter the dental surgery, would be beneficial for your child, please do not hesitate to phone us at the above number.

If you would like to change your appointment time to an earlier or later time of day, please do not hesitate to contact us on the above number.

We have included some photographs of the dental clinic and staff, to familiarise your child with the dental experience.

An application, including a virtual tour of the dental clinic, and interaction with dental staff is available on Apple itunes™. If you have a smart phone or tablet device, you may download this for free. An Apple iPad™ with this application is available in the waiting room at Highlands Dental Clinic, for your child to use while in the waiting room. Access to this application is also available on our website:

<http://www.chcphull.nhs.uk/>

1. Has your child attended dental services in the past?

Yes No

2. If yes, have you experienced difficulty in accessing this dental service?

Yes No

3. If you have experienced difficulties, please describe them in the space provided:

4. Would it be difficult for your child to wait in the dental waiting room?

Yes No

5. Would it make a difference for your child if the dental waiting room were busy?

Yes No

6. Which of the following times would be most suitable for your child's dental appointment?

- First thing in the morning
- Mid morning
- First thing after lunch
- Mid afternoon
- Last thing in the afternoon

7. Is your child's behaviour liable to change suddenly?

Yes

No

8. If yes, is this behaviour change associated with any of the following triggers? (Please include all that are appropriate)

- No reason
- Bright lights
- Loud noise
- Having his/her head touched
- Strange tastes
- Strange smells
- Enclosed spaces
- Dental gloves
- Dental mask

9. If yes, please indicate which of the following behaviours your child may display (please tick all that are appropriate):

- Crying
- Self-harming
- Headbutting
- Biting
- Spitting
- Laying on the floor
- Hitting/lashing out
- Positive behaviour

10. Do you have any specific behaviour management techniques that you use with your child, such as counting to ten or stop signals?

Yes No

11. If yes, please describe these technique/s in the space provided:

12. Is your child happy to wear protective glasses?

Yes No

13. Is your child happy to lie back on the dental chair?

Yes No

14. Is your child happy to have his/her mouth examined?

Yes No

15. Is your child happy to accept air/water in his/her mouth?

Yes No

16. Would your child be happier if we showed him/her the dental equipment beforehand?

Yes No

17. Is your child happier to be seen by the same dentist and dental nurse on each visit?

Yes No

18. Do you know when your child is in dental pain?

Yes No

19. How does your child communicate? Please indicate all appropriate answers:

- Speech
- Makaton
- Picture Exchange Communication System (PECS)?
- Does not communicate
- Other _____

20. Which, if any of the above means of communication does your child use most often?

21. Do you have any other information about your child and his/her preferences/potential behaviour that would be beneficial for the dentist to know about, prior to the dental visit?

Thank you for your help!

Appendix 11

My visit to Highlands Dental Clinic



Read this social story with your child to familiarise them with the dental visit.

City Health Care Partnership



Today I am going to the dentist.

My parents and I will drive to the building with the green door.



I will go to reception and will give my name.



I will wait in the waiting room.

There are toys for me to play with.

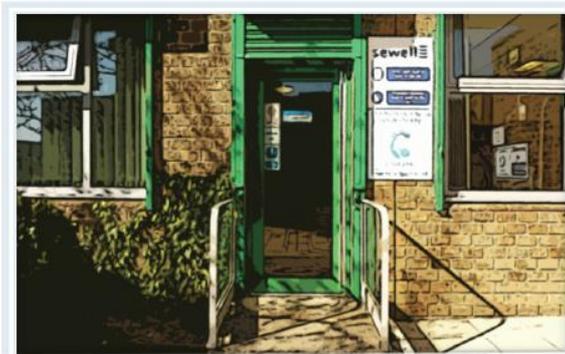


When the nurse calls me I will walk down the hallway to see the dentist.



My dentist will say hi to me. I will sit on the big chair, and lie still.

The dentist will count my teeth.



I did very well at the dentist.

Now it is time to go.

Appendix 12

Front door of Highlands Dental Clinic, Hull



Appendix 13

Waiting room in Highlands Dental clinic, Hull



Appendix 14

Reception desk at Highlands Dental Clinic, Hull. The receptionist (Rachel Mattinson) and the dental nurse (Laura Leng) are present.



Appendix 15

Corridor to Dental Surgery, Highlands Dental Clinic, Hull



Appendix 16

Dental surgery, in Highlands Dental Clinic, Hull. The dentist (Siobhan Barry) and the dental nurse (Laura Leng) are present.

