Investigating Dental Anxiety in Individuals with Autism Spectrum Disorders

Lama A. Sahab

A thesis submitted in partial fulfilment of the requirement of the University of Reading for the degree of

Doctor of Philosophy

School of Psychology and Clinical Language Sciences

October 2017

Declaration

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged. This thesis has not been previously submitted for another PhD or comparable academic award.

I acknowledge the use of proof reading services.

Signed on the 2nd of October 2017

Abstract

Dental anxiety is a common and disabling problem for individuals with autism spectrum disorders (ASD). Little is known about the causes of dental anxiety in ASD but the literature suggests it may be related to sensory sensitivity (Stein et al., 2011) and having high rates of anxiety in general (White et al., 2009). The purpose of this research is to examine the factors that predict dental anxiety in children with ASD.

The first two qualitative studies were designed to identify relevant factors in dental anxiety using a bottom-up approach. Interviews were carried out with parents of children with ASD and individuals with ASD. The second study interviewed dentists with varying expertise in ASD. Both sets of interviews were analysed using content analysis. Findings from the qualitative studies suggest that dental anxiety is related to parental anxiety, sensory sensitivity, worries about pain, and negative experiences.

In the third study 45 children with ASD aged (11 to 17) and their parents, and a comparison group of 50 Typically Developing (TD) children and their parents, completed measures examining dental anxiety and associated factors. The results demonstrate that children with ASD have higher rates of dental anxiety related to their higher overall anxiety level. Correlations show that dental anxiety is related to other forms of anxiety: unusual sensory processing, cognition, past experiences at the dentist, parents' dental anxiety, and the number of visits that a child has had to the dentist. Regression analysis shows that dental anxiety in children with ASD is determined by their worries about treatment and the number of dental visits. In TD children, dental anxiety was only predicted by their worries about treatment. Nevertheless, despite the aforementioned small differences, this third study showed that children with ASD and TD children are more alike than different, which is an interesting finding that requires further investigation.

Overall, this research helps us understand the underlying causes of dental fear in children with ASD and gives insight into interventions to support them with oral care.

Acknowledgments

"Whoever does not thank people has not thanked God" (Prophet Muhammad-pbuh).

The writing of this thesis has been one of the most significant personal and academic challenges I have faced. For this, I am grateful to Allah Almighty for providing me with the determination to complete this thesis. I also thank my supervisors Dr Fiona Knott and Dr Timothy Williams who were always available whenever I encountered problems or had a question about my research or writing. They consistently allowed this research to be my own work, but steered me in the right direction whenever they thought I needed it.

I am grateful to the Saudi Cultural Bureau in London, and to the King Abdullah Foreign Scholarship Program (KAFSP), who provided the funding for this PhD.

The PhD has been demanding, and there have been many moments when I thought I could not complete it, but because of my great family who always believed in me and supported me I have achieved my goal. I would like to express my heartfelt thanks to my beloved parents, Eatidal Baeshen and Abdulahakim Sahab, for their blessings and for their continuous support, and for always encouraging me and believing in me and all my accomplishments.

My sincere gratitude to Deema, Dara, Mohamed, Nour, Abdullah and Dala and all the family for giving me the support and confidence to finish the research.

Special thanks are due to my best friend and colleague, Reem Balubaid, who supported me through it all despite the enormous work pressure we were both facing. I also want to express mydeepest thanks to my Reading family, the Fatanais', who made me feel at home: Raoom, Sahal, Sabaa, Saofian, and Noura, who are special. Thanks to all my friends and colleagues and their invaluable assistance and support through this journey: it would have not been the same without you.

I wish also to express my appreciation and thanks to the Department of Psychology, who provided the support and equipment I needed to complete my research. I offer my sincere gratitude to the participants who took part in this study for their patience and enthusiasm.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

ASD	Autism Spectrum Disorders
TD	Typical Developing
ABA	Applied Behaviour Analysis
ToM	Theory of Mind
EF	Executive Functioning
WCC	Weak Central Coherence
CFSS-DS	Children Fear Survey Schedule-Dental Subscale
SCAS	Spence Children Anxiety Scale
SP	Sensory Profile
DCQ	Dental Cognitive Questionnaire
DEQ	Dental Experiences Questionnaire
HADS	Hospital Anxiety and Depression Scale
DAS	Dental Anxiety Scale
SCQ	Social and Communication Questionnaire
APA	American Psychiatric Association
HFA	High Functioning Autism
LFA	Low Functioning Autism

List of Appendices

1 Chapter One

Autism Spectrum Disorders and Dental Anxiety: Literature Review

1.1 Motivation behind the study

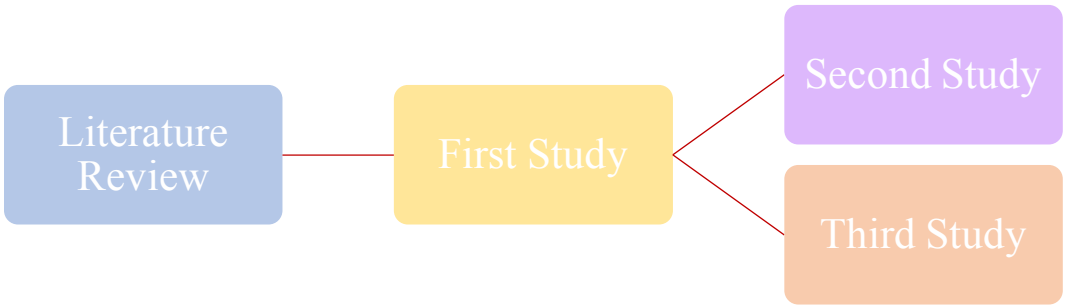
Children and adults with autism have significant problems with oral hygiene and dental care and often experience high levels of dental anxiety (Cagetti et al., 2015; Carrillo-Diaz, Crego, Armfield, & Romero, 2012; Mayes et al., 2012). Although common in the typical population, these problems are magnified in individuals with autism spectrum disorders (ASD) leading to high rates of dental caries and poor oral health (Jaber, 2011). Dental anxiety may mean that individuals with ASD avoid dental visits, exacerbating the risk of dental problems and pain (Armfield & Heaton, 2013; Lu, Wei, & Huang, 2013; McKinney et al., 2014). However, although the importance of dental care is well understood, there is still relatively little understanding of the high rates of dental anxiety in this population. The present thesis aims to explore the reasons for dental anxiety from the perspective of those with autism, their carers and the dentists who support them.

This topic became an area of interest to the researcher as she observed a number of children with ASD having problems maintaining their oral health while working in an Applied Behaviour Analysis clinic (ABA) is Saudi Arabia. The researcher noticed that some of them had problems brushing their teeth and many of them never visited the dentist. In addition, she was given the task of teaching a child who had trouble with his teeth how to brush them, as his parents had complained of his bad oral health and were planning to put him under general anaesthesia for dental treatment. From this experience, the researcher was determined to know what caused this fear of dental visits held by children with ASD, in order to help them with this essential aspect of their lives.

The researcher investigated dental anxiety in individuals with autism through three studies. Following a discussion of the background to autism in this chapter, Chapter 2 explores the

nature of anxiety in both typical development (TD) and ASD, with a particular focus on dental anxiety. In the first study of this thesis, parents of children with ASD and individuals with ASD themselves were interviewed about their experience of dental treatments and dental anxiety, to elicit factors that they felt were relevant and important. In the second study, the researcher interviewed dentists to gain their view on the causes of dental anxiety and the interventions that seem most effective with individuals with ASD. The factors highlighted by these interviews and in the literature were then examined in the third study which compared adolescents with autism and typical development. This study aimed to explore differences in the experience of dental anxiety between these groups and to identify factors that predict dental anxiety, in order to contribute to the development of effective techniques to support individuals with autism during dental treatment.

1.2 Overview of the trajectory and sequence of the research



The literature review was carried out from the beginning and throughout the four years. The researcher firstly completed the first qualitative study, which contributed to the development of the following studies. Studies Two and Three were completed in parallel and that was due to time restrictions and difficulties in recruitment.

1.3 The impact of dental anxiety

A study conducted in the United Kingdom (UK) found that 11.6% of the population suffer from high dental anxiety and that anxiety about treatment can increase for individuals who do not visit the dentist regularly (Humphris, Crawford, Hill, Gilbert, & Freeman, 2013). Anxious

individuals are also more difficult for dentists to manage since they are generally less cooperative (Armfield & Heaton, 2013; Humphris, Spyt, Herbison, & Kelsey, 2016).

The administration of dental care becomes even more complex when the individual is diagnosed with a disability (Cagetti et al., 2015). Individuals with autism spectrum disorder (ASD) are likely to have more frequent and more severe problems with dental anxiety than their TD peers, due to the behavioural and psychological symptoms that the ASD disability presents (Cagetti et al., 2015; Mayes et al., 2012).

As is discussed in this study, ASD is marked by reduced abilities in some aspects of verbal communication (Dua, Jindal, & Saini, 2016), which can mean, for example, that such children find it more difficult to express dental pain. Research has also found that children with ASD are more likely to demonstrate behavioural problems during the visit (Armfield & Heaton, 2013;Du, Yiu, Wong, & McGrath, 2015; Humphris et al., 2016). Anxiety is recognised amongst the most frequent comorbid conditions of individuals with ASD (Grondhuis & Aman, 2012) and can therefore present a particular challenge for dental treatment (Blomqvist, Dahllöf, & Bejerot, 2014).

This chapter will begin by discussing the importance of oral health, defining autism, characteristics of autism, prevalence of autism, causes of autism, psychological theories of autism, and comorbidity in autism.

1.3.1 Significance of oral health

The significance of oral health is reflected in the numerous health implications that can arise in children, whether they are TD or have ASD, if proper dental hygiene is not maintained (Ljaljević, Matijević, Terzić, Anđelić, & Mugoša, 2012). For example, dental caries left unattended in children have been found to affect weight gain and growth, the latter factor being a consequence of disrupted sleeping patterns due to sensations of pain or irritation (Sheiham, 2006). Further, overall wellbeing and happiness have also been found to be correlated with good oral hygiene (Dumitrescu, Kawamura, Dogaru, & Dogaru, 2010).

Most studies demonstrate that children with ASD have poor levels of dental hygiene, often due to their behavioural problems and unwillingness to accept dental treatment (Cagetti et al., 2015; Delli, Reichart, Bornstein, & Livas, 2013; Loo, Graham, & Hughes, 2009), although this can also result from their diet, oral hygiene practices or age (Gandhi & Klein, 2014). Although there may be a link between caries and psychoactive medications often taken by children with ASD, no causal link has yet been established by research (Marshall & Mancl, 2010).

A few studies have, however, found conflicting results regarding oral hygiene. For example, oral health screening of preschool children in Hong Kong found that those with ASD had a reduced occurrence of caries and better gingival health than their TD peers (Du, Yiu, King, Wong, & McGrath, 2014). There may have been various reasons for this particular outcome. For example, that sample only included children who 'could cope with' oral health screening (Du et al., 2014) and this could suggest children with more severe ASD, and consequently more severe behavioural problems, may have poorer standards of oral health. Delli et al. (2013) believe the conflicting results in studies could be attributable to methodological issues such as sample size, a lack of non-autistic control groups, as well as differences in anxiety measurement tools.

1.3.2 Unmet dental needs

By analysing national survey data of 2772 American children with ASD, McKinney et al. (2014) confirmed their hypothesis that unmet dental needs among children with ASD are partly related to the difficulty of obtaining a paediatric dentist who is willing and/or able to provide appropriate care for children with ASD, especially when there are severe levels of ASD in areas of intellectual, communication and behaviour difficulties. In a mail-in questionnaire survey measuring the unmet dental needs of 555 children on the North Carolina Autism Registry, 12 percent had unmet dental needs; the barriers identified by that study in terms of

treatment included cost, lack of insurance and the child's behaviour (Lai, Milano, Roberts, & Hooper, 2012).

In a study of a randomised sample of 347 preschool children with ASD in Hong Kong (Du et al., 2015), the feasibility of conducting oral health screening was positively related to levels of cognitive, social, communication and reading skills; most importantly, it was negatively related to challenging behaviours and reduced cognitive functioning. These results indicate that parents of children with ASD are in urgent need of referral to dental providers who specialise in serving this population. In the United States and Canada, studies on the preparation of dentists for treating children with ASD indicate that, whereas most dentists educated prior to 2000 felt unprepared to treat children with ASD, most dental schools are now educating students on how to properly care for their patients with ASD (Delli et al., 2013).

It has been noted that many children with ASD do not receive dental care because of their fear of dental practices (Isong et al., 2014). Consequently, it has also been observed that the oral hygiene of children with ASD may make them more susceptible to developing dental diseases (DeMattei, Cuvo, & Maurizio, 2007). Concerns about this are reinforced by studies that have shown a higher prevalence of dental caries in individuals with ASD, in addition to poor oral hygiene (Jaber, 2011) and a higher predisposition to bruxism (El Khatib, El Tekeya, El Tantawi, & Omar, 2013).

This first section has outlined the scope of the problem regarding dental care for individuals with ASD. In order to set the context for the exploration of dental anxiety in this thesis, the remainder of this chapter discusses the background and characteristics of ASD in order to highlight aspects that are important in understanding anxiety.

1.4 Definition of autism

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects social communication and social interaction in many spheres of life (Kim et al., 2014). Indications of ASD include impaired abilities in the intrapersonal and emotional reciprocity, deficits in nonverbal interaction for the purpose of socialisation and a lack of building, sustaining, and

understanding relationships. In addition, children with ASD usually develop repetitive and limited patterns of behaviour, activities and hobbies (Kim et al., 2014).

1.5 History and diagnosis

Between the 1960s and 1980s, scholars increasingly tried to understand the causes of autism, and this period marked the search for definitions in order to improve diagnosis. Many still saw it as a manifestation of schizophrenia, meaning autism was not included as a separate disorder in the first two DSM manuals (APA, 1952; APA, 1968). Following Rutter's redefinition of autistic symptoms, autism was finally included as a separate disability in the DSM's third edition (APA, 1980).

The two main diagnostic classification systems used to diagnose autism include the International Classification of Diseases and Related Health Problems (ICD-10) and Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5). The definition of autism based on the ICD-10 is discussed in the following paragraph. In addition, the difference between the DSM-5 and ICD-10 criteria is reviewed below.

The World Health Organisation (Regier, Kuhl, & Kupfer, 2013) identifies the characteristics of autism in the International Classification of Diseases (ICD-10, Appendix 1, p.223). Autism is classified in Section F84 under the category of 'pervasive developmental disorders', which include childhood autism, atypical autism, Rett's syndrome, other childhood disintegrative disorders, overactivity disorder associated with mental retardation and stereotyped movements, Asperger's syndrome, other pervasive developmental disorders, and pervasive developmental disorders unspecified.

According to ICD-10, a diagnosis of autism is usually made before the child reaches the age of three years and is marked by three main characteristics. The first is abnormal development in social interaction and attachment; the second is impaired communication; and the third involves an absence of symbolic play involving make-believe, social imitative play or a lack of creativity (WHO, 2010). Impairments in communication can include a lack of eye-to-eye contact, and failure to display changes in facial expression or intonations of speech. There

is usually a repetitive and idiosyncratic use of words or phrases. Repetition is also found in the children's behaviour and they typically show a rigid and compulsive adherence to their day-to-day routines and rituals. The rituals can involve a preoccupation with dates, timetables or numbers, as well as repetitive physical actions such as a flapping of the hands or moving their whole body (Kim et al., 2014).

Children with ASD can become distressed when there are changes in their routine, even with the smallest details, for example if their belongings are moved slightly out of order. It is also very common for children with ASD to be preoccupied with the touch or texture of an object rather than the actual object itself. Together with specific diagnostic characteristics, children with ASD can display fear, anxiety and self-injury. Many children with ASD also show learning difficulties and cognitive impairment (Kim et al., 2014).

Various studies have also found a relationship between ASD and Intellectual Quotient (IQ). For example, Charman et al. (2011) found that 16% of individuals with ASD had moderate to severe intellectual disability with an IQ under 50, compared with just 0.13% of the ordinary population (Langtree, 2014). 55% of children with ASD had IQs under 70 (compared with 15.7% in the ordinary population), 28% of children with ASD had average intelligence (between 85-115 IQ points) (compared with 68.3% in the ordinary population), while only 3% had above average intelligence of over 115 IQ points (compared with 15.9% in the ordinary population).

These findings suggest that, while individuals with ASD may have lower IQ levels overall, the presence of ASD does not necessarily mean they have poor intellectual functioning in general; some individuals with ASD may possess higher levels of intelligence than the ordinary TD population. The literature does, however, show that IQ can affect social behaviours. Hallett et al. (2013) used the *Child and Adolescent Symptom Inventory* scale on a sample of 415 children with ASD to find that those with IQs over 70 were more likely to be irritable and hyperactive, to demonstrate impaired or inappropriate speech, and to be more

anxious than their lower functioning peers. These findings have implications for the management of dental treatment for children with ASD.

The most recent version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) was published in 2013 and, in contrast to its predecessor and the current ICD-10, replaced the separate diagnostic labels of Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder and Not Otherwise Specified (PDD-NOS) with a single umbrella term known as 'Autism Spectrum Disorder'. This was due to feedback which found that the definitions were not sufficiently precise and that different clinicians were diagnosing the same individual in different ways (Autism Research Institute, 2016). Changes to the DSM-5 also arose from studies that found PDD subtypes differed in symptom severity and IQ (Tsai, 2014). Rather than diagnosing specific conditions according to symptoms, the severity of the ASD is assessed by levels, according to the level of challenges experienced by the individual and the amount of support they need (Volkmar & McPartland, 2014).

As such, the DSM-5's new umbrella term covers the separate categories that still exist within the ICD, namely Autistic Disorder, Asperger's Syndrome, Other Childhood Disintegrative Disorder, Other Pervasive Developmental Disorders and Pervasive Developmental Disorders, Unspecified. Both systems recognise similar criteria although they use different systems to classify them, with the ICD providing a brief overview of pervasive developmental disorders and then identifying the traditional sub-categories as a basis for diagnosis.

The DSM-5 focuses on symptoms rather than categories, which has led it to expressly include a criterion of sensory sensitivity within the ASD classification. Section B covers restricted and repetitive behaviours and interests and B4 outlines behaviours such as hyper- or hypo-reactivity to sensory input or an unusual interest in sensory aspects of the environment (APA, 2013, p.50). These sensory behaviours were not included as criteria under any of the separate disorders listed in the DSM-IV. The DSM-5 has also relaxed the age onset criteria and in Section C states that the symptoms of ASD would have been present by or before the age of

eight years old. The DSM-IV stated Autistic Disorder would have been visible by the age of three years and grouped disorders with a later age onset under the general PDD-NOS category. The DSM-5 also recognises expressly that the symptoms may not become fully manifest until the child encounters a challenging social situation (APA, 2013).

1.6 Prevalence of autism

As reports of the prevalence of autism have increased, the subject has drawn increasing academic attention (Matson, Tureck, Turygin, Beighley, & Rieske, 2012). There is currently no UK public health record that provides an exact number of children diagnosed with ASD. Researchers have therefore estimated prevalence using different methods such as parental reports (Russell, Rodgers, Ukoumunne, & Ford, 2014) and different studies have found different prevalence rates: for example, a study using parent-reports conducted by Russell et al. (2014) in the UK found the estimated prevalence of ASD to be 1.7%, which is high considering prevalence was only thought to be 0.05% up until 1980 (Rutter, 2005).

A recent study in the UK considered the changing prevalence rates of autism over time and found that, while there was a sharp increase during the 1990s, prevalence rates were stable in the early 2000s and remained constant through to 2010, at a rate of 3.8 per 1000 for boys and 0.8 per 1000 for girls (Taylor, Jick, & MacLaughlin, 2013). This is in significant contrast to estimates made by the Center for Disease Control in the United States (during 2011-12), which found the prevalence of autism among children aged 6–17 years to be one in 50 (Blumberg et al., 2013).

Russell et al. (2014) argued these increases could be due to various factors, such as growing awareness about the condition, better and more successful diagnosis of children at a younger age, and the broadening of autism criteria. Prevalence rates are also affected by the tools used to measure ASD and it is recognised that prevalence rates vary worldwide (Russell et al., 2014). Won, Mah and Kim (2013) consider that studies have shown ASD prevalence to be approximately 1% worldwide. Similar figures have been confirmed by other studies (Geschwind & State, 2015).

The increasing prevalence of ASD has therefore been the subject of much debate. Clearly changes and clarification in diagnosis have facilitated identification, although authors have also cited increased funding for ASD services (Shattuck, 2006; Matson & Sturney, 2011), growing awareness among parents (Matson & Sturney, 2011), and particular ethnic sub-groups (Rice et al., 2012) as contributory factors to changing prevalence rates.

1.7 Causes of ASD

ASD is identified by symptoms rather than aetiology and although converging evidence points to genetic causes, the heterogenic nature of the findings implies multiple types of ASD along with multiple routes of causation (Won et al., 2013). For many years, the causes of ASD were relatively unknown. In line with what Donovan and Zucker (2016) termed the 'blame game', the refrigerator theory was an early suggestion put forward by Bettelheim, suggesting that a failure of parents to bond with their children produced autistic symptoms (Bettelheim, 1967; Stace, 2010). However, a 1977 study on twins established the first links between ASD and genetic factors (Folstein & Rutter, 1977).

However, figures regarding the influence of genes have varied. For example, Larsson et al. (2005) undertook a longitudinal study involving all children born in Denmark after 1972. The methodology included investigating the genetic cause of ASD and incorporated twin studies, as it would be expected that monozygotic twins would have a 100% concordance rate, although the actual figure they found was 36% for monozygotic twins (identical twins) and 3% for dizygotic twins (non-identical twins). Twin studies are important because they suggest that, although genes are important, other causes must exist as well. A notable strength of Larsson et al.'s (2005) study is the large population size employed, making it highly representative of children and their parents in Denmark. The data was also sufficiently objective due to the way that healthcare records are organised in the country and it therefore did not rely on retrospective accounts by parents, which may have been inaccurate.

Other studies have found the concordance to be much higher, with some suggesting concordance rates for monozygotic twins to be between 60-90% (and between 2–10% for

dizygotic twins) (Mazefsky, Goin-Kochel, Riley, Maes, & Autism Genetic Resource Exchange Consortium, 2008). Other studies have suggested ASD is 80-90% genetic (Kroncke, Willard, & Huckabee, 2016). These variances may be a result of methodological differences in the way in which the samples were selected; for example, by selecting groups on the basis of particular characteristics (such as language delay) as opposed to empirically, based on behavioural genetic analyses (Mazefsky et al., 2008). Despite the variance in the findings, these studies show genes cannot be the only cause of ASD (Larsson et al., 2005). As such, this begs the question of what factors are also relevant to ASD aetiology.

In terms of environmental causes, these factors include those that are non-genetic, such as viruses, medications and chemicals, as well as social and cultural variables (Lyall, Schmidt, & Hertz-Picciotto, 2014). The number of studies on environmental factors has increased exponentially in the last decade and they have tended to indicate that environmental exposures during critical time periods of neurodevelopment are causal, such as exposure to air pollution or pesticides, or malnutrition during the preconception and prenatal periods (Lyall et al., 2014).

For example, some studies have found an association between an increased risk of ASD and perinatal factors, such as alcohol, rubella, low birth weight, Caesarean section and congenital malformations (Larsson et al., 2005). These studies are useful since they identify active measures that parents can take to reduce the likelihood of ASD. Much of the awareness of the risk from non-genetic studies has also come from studies conducted on monozygotic twins (Kim & Leventhal, 2015). A further risk factor identified was parental psychiatric history, specifically, conditions such as schizoid personality traits and mothers with schizophrenia (Larsson et al., 2005).

Regarding possible environmental causes, there was a public controversy regarding the possibility of a causal link between childhood vaccines and ASD, which began with a widely publicised study which was later retracted by its head author in the *Lancet* (Wakefield et al., 1998; Wakefield, 1999). This view was strengthened when a decision in the US Federal Court led to the parents of Hannah Poling winning a lawsuit, where they argued that their daughter

developed autism after a series of vaccines (Donovan, 2010). Wakefield, whose study claimed to link the Measles-Mumps-Rubella (MMR) vaccine with autism, was later found guilty of institutional research misconduct (Godlee, Smith, & Marcovitch, 2011) and the findings were further discredited by a study comparing Japanese children aged between 1-36 months with and without ASD, which found no associations between the MMR vaccination, thimerosal dosage and an ASD diagnosis (Uno, Uchiyama, Kurosawa, Aleksic, & Ozaki, 2015).

A meta-analysis of case-control and cohort studies also concluded there was no credible association among the application of thimerosal, mercury or MMR and the subsequent development of autism or ASD, when grouped by condition or exposure type (Taylor, Swerdfeger, Eslick, & 2014). These views were supported by the fact that the MMR vaccine had the allegedly problematic chemicals removed yet ASD rates continued to rise (Kroncke et al., 2016). The belief in vaccines as the cause may have been encouraged by the fact that some regressive forms of autism manifest when a child is two years old, at around the same time when vaccines are being administered.

1.8 Theories regarding the psychological underpinnings of ASD

There are several psychological theories that have been put forward to explain ASD. This thesis will focus on the three which are most researched and articulated: Theory of Mind, Weak Central Coherence and Executive Functioning.

1.8.1 Theory of Mind (ToM)

To explain the impairment of social functioning in children with ASD, the Theory of Mind (ToM) has been proposed. Non-disabled children typically develop an understanding from the second year of life that other people may have different emotions, desires or beliefs to them, which is referred to as a ToM (Baron-Cohen, Leslie, & Frith, 1985). Premack and Woodruff (1978) (as cited in O'Nions, Sebastian, McCrory, Chantiluke, Happé, & Viding, 2014) described ToM as the potential to assign the mental states of others and anticipate and predict their behaviour. It is widely reported in the literature that children with ASD do not

appear to have a highly developed ToM (Baron-Cohen et al., 1985) and often have delays in the development of this capacity, which has also been described by Baron- Cohen (2009) as the 'mind-blindness' theory. The methodology used to test this has included whether the child can or cannot understand the concept of holding a false belief or a belief that differs to one held by another person.

It is argued that being able to understand another person's state of mind is essential to developing social skills and relationships (Baron-Cohen et al., 1985). The mind-blindness theory suggests that the delay in the development of ToM makes the understanding of other people more difficult and therefore makes it more likely that they will find the behaviours of other people confusing, unpredictable or even frightening. Frith (2004) suggests that high-functioning individuals with Asperger's Syndrome also lack an intuitive ToM, although they can learn how to demonstrate an explicit ToM by giving appropriate answers using logical deductions (Frith, 2004).

At the time of its publication, Baron-Cohen et al.'s (1985) study was considered a revolution for ASD research and several studies confirmed the ToM hypothesis (Tager-Flusberg, 2001). Baron-Cohen's findings were also extended to other mind-reading tasks than false beliefs (Baron-Cohen, 2000). Baron-Cohen continued to argue for his theory in a paper written in 2001, where he discussed the features of an abnormal ToM and stated the need for developmentally appropriate tests to diagnose it.

However, as the literature on ASD has increased, some have become sceptical over the theory's ability to explain the primary symptoms of the ASD disability (Tager-Flusberg, 2001). For example, it did not account for some of the behaviours found within this population, such as limited interests and heightened attention to detail (Baron-Cohen, 2009). Questions were also raised as individuals suffering from other disorders also display a degree of mind-blindness, such as those with schizophrenia. Further, it did not fully explain the dynamics of empathy which, as stated, requires both an understanding of another person's state of mind, and an appropriate emotional response to it (Baron-Cohen, 2009).

To meet these concerns, a new theory was introduced by Baron-Cohen (2002), which explains the communication and intrapersonal difficulties in individuals with ASD, referring to difficulties and delays in empathy, in addition to explaining the aspects of strong points that refer to central or greater ability in systematising (Baron-Cohen, 2002; Baron-Cohen, 2009; Grove, Baillie, Allison, & Baron-Cohen, 2013). As its name suggests, the Empathising-Systemising Theory (E-S) (Baron-Cohen 2009) makes a distinction between empathising and systemising and asserts that individuals with ASD have delays in the ability to empathise, yet display superior skills in systematising, which accounts for their strengths in non-social areas (Baron-Cohen, 2009). Some studies have noted that people with ASD have greater difficulty with 'cognitive empathy' (identifying and understanding the feelings and beliefs of others and understanding why they feel this way) than 'affective empathy' (the ability to respond in a way that is appropriate to the other person's mental state) (Mazza et al., 2014). The concept of empathy in the new theory fills the gaps left by the ToM in terms of affective empathy.

Baron-Cohen (2009) defines systemising as the ability to identify the rules that govern a phenomenon, in order to predict how it will behave and to control it (Grove et al., 2013). This aspect has been shown to be particularly strong in individuals with ASD and can help to explain their preference for routine (Kim et al., 2014).

1.8.2 The Weak Central Coherence (WCC) Hypothesis

Although not part of the ICD and DSM-5 diagnostic criteria, unusual perceptual processing is often identified in individuals with ASD. First proposed by Frith (1989), the Weak Central Coherence Hypothesis (WCC) refers to the theory that people with ASD pay more attention to local features than global in both perceptual and cognitive processing and that executive functions (EF) responsible for interpreting parts as part of a greater whole are not as strong as in TD individuals (Van der Hallen, Evers, Brewaeys, Van den Noortgate, & Wagemans, 2015). EF is further discussed later in this chapter.

WCC models suggest that perceptual, social and cognitive functioning are different in children with ASD due to their brains' preference to pay attention to details instead of the overall image (Vanegas & Davidson, 2015). Research has found that children with ASD make more mistakes in tasks that require the use of context while pronouncing words and completing sentences (Booth & Happe, 2010), but can perform faster than TD children on tasks that require disengagement from a larger, meaningful picture (in order to find an obscured image), known as the Children's Embedded Figures Test (CEFT) (Keehn, Brenner, Ramos, Lincoln, & Marshall, 2009). Research has also found differences with the CEFT between ASD and high functioning autism (HFA) groups (Planche & Lemonnier, 2012).

Since the original model by Frith, several alternatives have been put forward, such as Enhanced Perceptual Functioning (EPF) (Mottron, Dawson, Soulieres, Hubert, & Burack, 2006). This perspective concurs with the view that individuals with ASD pay more attention to local cues than global ones although the latter does not suggest there is a deficit in global abilities altogether (Almeida, Dickinson, Maybery, Badcock, & Badcock, 2014). EPF suggests the individual with ASD perception is due to enhanced capabilities in low-level perceptual processing, which result in greater basic perceptual skills (such as detection and discrimination). Some scholars have suggested that the difference between these views stems from the fact that the concept of 'global processing' has been interpreted widely and this has presented difficulties when trying to reconcile studies in this field (Milne & Szczerbinski, 2009).

Despite this, findings regarding EPF have led some to suggest that WCC is merely processing bias, which can be overcome when global processing is explicitly required (Hadad & Ziv, 2015; Koldewyn, Jiang, Weigelt, & Kanwisher, 2013). For example, research by Hadad and Ziv (2015) found that individuals with ASD were better able to follow instructions in the 'Garner task' (which tests an individual's ability to process a 2D rectangle) than the TD group, which demonstrated a strong bias for global processing. One of the strengths of that study was that it combined two separate tasks with the same group of participants, which enabled the

researchers to reduce the effect of the bias that can arise from the Garner task alone (Hadad & Ziv, 2015).

1.8.3 Executive Functioning

Considerable converging evidence suggests that people with ASD exhibit difficulty with Executive Functioning (EF), which refers to the controlling functions that upper-level brain structures have on overall neural operations (Hollocks, Ozsivadjian, Matthews, Howlin, & Simonoff, 2013). Executive functions include the ability to maintain attention, prioritise, see the 'bigger picture', plan and apply oneself, engage in self-monitoring, and control impulses (Semrud-Clikeman, Fine, & Bledsoe, 2014). However, it is also regarded as "an umbrella term covering several interrelated but distinct higher-order cognitive functions" related to regulation of thoughts and actions (Van Eylen, Boets, Steyaert, Wagemans, & Noens, 2015, p.1400).

For example, where a TD child may be able to engage in one task and then easily switch to another that has different rules, children with ASD are likely to become rigid and demonstrate a preference for completing the same task in the same way over and over (Hahn & Bentley, 2013). This preference has also been explained by systemising theory, which suggests that children with ASD prefer to use rule-driven strategies to acquire and apply new information (Vanegas & Davidson, 2015).

Whereas TD children are able to inhibit themselves (such as by 'waiting their turn' or 'waiting until later' by the age of four), children with ASD find it more difficult to curb their desire for their preferred activity. Children with ASD also find it more difficult to complete tasks that require a lot of working memory. For example, a parent of a TD child may be able to tell them to 'get ready for school' and this will result in the child remembering they have to brush their teeth, put on their uniform and pack their bag, etc. Even after hundreds of practices however, a child with ASD will still struggle with getting ready on their own (Cowan, 2014; Lever, Werkle-Bergner, Brandmaier, Ridderinkhof, & Geurts, 2015).

However, the study of EF and its association with ASD is difficult due to the fact that many different definitions of EF co-exist (Van Eylen et al., 2015). Many studies have examined various aspects of EF (such as inhibition, flexibility, generativity, working memory and planning) although few have examined all these factors together. As such, studies have tended to yield inconsistent results, most likely because different tasks were used to measure each aspect of EF (Van Eylen et al., 2015). Despite this, studies have converged in finding that problems with EF are more common in cognitive flexibility tasks and tasks that require a shift from one frame of thought to another (Reed, Watts, & Truzoli, 2013; Rosenthal et al., 2013).

Age-related differences in EF appear to be associated with the types of tasks that children with ASD have trouble with; inhibition problems are more common in children aged 6-8, reduced cognitive flexibility in ages 9-14, and planning problems in children of ages 12-14 (van den Bergh, Scheeren, Begeer, Koot, & Geurts, 2014). In addition, some of the measures of EF also correlate with IQ (Van Eylen et al., 2015) and age has also been related to EF performance (Best & Miller, 2010). As such, it is important to take age and IQ into account when designing appropriate methodologies into EF in individuals with ASD. Questions have also been raised about the ability of EF to account for ASD because there is a lack of consensus as to which aspects of EF are typical to ASD (Hill, 2004). EF dysfunction has also been found to be present in other disorders (such as ADHD) and this limits the degree to which EF may be used as an indication of ASD.

The psychological theories discussed here reflect scholarly attempts to explain ASD symptoms. However, none of them explain ASD in its fullness and the interrelationship between these theories remains unclear (Vanegas & Davidson, 2015). This may be due to the fact that the same behaviour may be explained in more than one way, for example, it has been speculated that difficulties with EF on inhibition tasks could be due to a reduced capacity to process arbitrary rules (Jones, Webb, Estes, & Dawson, 2013). Some scholars have recognised that these are psychological theories which were developed before the era of neuro-imaging

and, as such, they are expected to continue their evolution as they have done throughout recent history (Rajendran & Mitchell, 2007).

The sections above have discussed the ASD disability, its prevalence, causes and explanations. The next section will go on to discuss additional conditions that can arise comorbidly with ASD.

1.9 Comorbid Conditions with Autism

The term comorbidity describes the situation in which the same individual has two or more disorders (Matson & Nebel-Schwalm, 2005). Medical comorbidities are both more common as well as more difficult to detect in individuals with ASD. This is partially a result of the problems they experience when trying to communicate their experiences, but is also attributable to widespread under-diagnosis, often resulting from the misperception that comorbid symptoms are simply another aspect of ASD (Kohane et al., 2012). Misdiagnosis may have been challenged by overlapping diagnostic criteria in previous versions of the DSM; in some cases, there may be two separate disorders, in others there could be two manifestations of the same underlying neurological abnormality (Pinborough-Zimmerman et al., 2007).

Recent studies on twins have shown that up to 90% of children with ASD have a comorbid disorder (Lundstrom, Reichenberg, Melke, Rastam, & Kerekes et al., 2015). These may be either physiological or psychological comorbidities. For example, in their study of individuals within a hospital population, Kohane et al. (2012) found individuals with ASD had significantly higher rates of bowel disorders, cranial abnormalities and diabetes; and some research has linked these correlations to genetic factors (Cross-Disorder Group of the Psychiatric Genomics Consortium, 2013).

The Kohane et al. (2012) study relied on electronic record data from nearly 15,000 individuals obtained between 2001 and 2010. The study sample was significantly larger than most studies in this field and it confirmed many of the findings of previous studies. It is recognised, however, that the sample relied on had been admitted to hospital and this suggests

their symptoms overall had been relatively more severe than individuals who did not need to be admitted.

Children with ASD also show comorbid psychological disorders, the most common of which is anxiety (Simonoff et al., 2008). Anxiety will be addressed in detail in the next chapter. Other common psychological disorders include Attention Deficit Hyperactivity Disorder (ADHD); a condition that exhibits traits of hyperactivity and distractibility. Simonoff et al. (2008) revealed that 28.1% of children with ASD also had ADHD in a study that measured 255 children using structured assessments. Other research has found this to be between 20% and 70% (Charnsil & Sriapai, 2011; Sinzig, Walter, & Doepfner, 2009). The reasons for the variation between findings is unclear, although it could be due to the outcome of a significant overlap between the symptoms of the two disorders, which explains the possibility of a dual diagnosis in the current DSM-5 (Pinto, Rijsdijk, Ronald, Asherson, & Kuntsi, 2016).

Leyfer et al. (2006) studied 109 children with ASD between the ages of 5 and 17 years who met the criteria for autism in the Autism Diagnostic Interview-Revised, Autism Diagnostic Observation Schedule and DSM-IV-TR (Leyfer et al., 2006). The study did not specify whether the children had High Functioning Autism (HFA) or Low Functioning Autism (LFA), which may have affected the findings. The study found that 37% had Obsessive Compulsive Disorder (OCD) and of this the most common form was rituals involving another person, where for example, parents would be required to act or respond in a certain way every time. It is interesting to note that both ASD and OCD are hallmarked by repetitive behaviours, although differences exist between the pathologies, and repetition in OCD is generally a result of distressing and intrusive concerns, whereas repetitive behaviours may not be a cause of concern for children with ASD (Ruzzano, Borsboo, & Geurts, 2015).

Lower rates have generally been found for depressive disorders in children than young adults. For example, in a study by Simonoff et al. (2008), rates of Major Depressive Disorder were found to be 0.9% amongst children with ASD, while a study conducted on young adults with Asperger's syndrome by Lugnegard, Hallerback and Gillberg (2011) found the rate to be

70%. This may be that the individuals with ASD in the latter study were much older, but it could also have been affected by the way depression was measured. For example, the latter study measured whether the individual had at least one depressive episode. The study by Simonoff, et al. (2008) examined whether major depression was a permanent comorbid diagnosis. 28.1% of children with ASD have been reported as affected with Oppositional Defiant Disorder (ODD) (Simonoff et al., 2008). Previous literature has noted familial links between ASD and schizophrenia and bipolar disorder (Sullivan et al., 2012). The relationship of bipolar disorder to ASD is still relatively under-researched and only a few cases have yet been reported (Leyfer et al., 2006). Again, this may be reflected in the very similar symptomology between the two conditions; where children with ASD often demonstrate changeable moods and emotions.

Research has also found significant relationships between ASD and psychotic disorders (Sullivan, Rai, Golding, Zammit, & Steer, 2013). This may be caused by genetic factors or the additional stress that arises from the manifestation of ASD symptoms (Selten, Lundberg, Rai, & Magnusson, 2015). However, the presence of psychosis in young children is rare and some research has found that this topic could not be meaningfully studied (Leyfer et al., 2006).

When additional pathologies go undiagnosed they can become chronic and make existing disabilities more challenging. Goldin, Matson, Tureck, Cervantes and Jang (2013), for example, found that children with comorbid ASD and ADHD were more likely to display tantrum behaviours than those with ASD alone. Gadow, DeVincent and Drabick (2008) found that children with ASD, ODD and ADHD exhibited worse symptoms than those who had solely ASD or ASD with only one other comorbidity. Individuals with ASD have a mortality rate that is between 3 and 10 times higher than the typical developing population and this is generally due to the comorbid conditions (Bilder et al., 2012; Gillberg, Billstedt, Sundh, & Gillberg, 2010; Woolfenden, Sarkozy, Ridley, Coorry, & Williams, 2012). However, comorbid psychiatric assessment is notoriously difficult in individuals with ASD, due to differing levels of IQ and

communication abilities, which can present challenges when caregivers seek to assess their mental state (Simonoff et al., 2008).

Research has also suggested there is high probability that individuals with ASD will exhibit comorbid anxiety symptoms (MacNeil, Lopes, & Minnes, 2009; White, Oswald, Ollendick, & Scahill, 2009). As dental anxiety is the subject of the present thesis, it is essential to understand the broad context of anxiety in ASD before exploring what is known about dental anxiety in more detail. In the next chapter, the epidemiology and models of anxiety in ASD and typical development will be overviewed, followed by a review of prevalence, causes and treatments of dental anxiety.

2 Chapter Two

The Road to Anxiety and Dental Anxiety: Literature Review

Anxiety is the primary focus of this thesis and is discussed in greater depth in this chapter. It addresses contextual information, the prevalence of anxiety in TD and ASD, models of anxiety in TD, models of anxiety in ASD, and the differences in anxiety between TD and individuals with ASD. The second half of the chapter focuses on dental anxiety in particular.

2.1 Anxiety

Anxiety is identified by the emotional and psychological nervousness regarding a specific stimulus or circumstance, which is associated with an enhanced feeling of physiological arousal (Spielberger, 2010). The Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5) (American Psychiatric Association; APA, 2013) defines various anxiety disorders that are commonly recognised in adolescents and children, including social anxiety, separation anxiety, specific phobias, agoraphobia, panic disorder, as well as others (DSM-5, 2013).

Anxiety in its various forms can affect social interaction with peers, educational achievement and a range of ordinary daily activities (Creswell, Waite, & Cooper, 2014). When left untreated, it can develop into a chronic illness in adulthood, leading to an increased risk of depression and substance abuse (Woodward & Fergusson, 2001). While some anxiety may be considered normal for children in general, it becomes pathological when it involves great distress or interferes with the child's daily tasks (Donnelly & Rhoads, 2012).

2.2 Prevalence of Anxiety

2.2.1 Prevalence of anxiety in TD children

Anxiety conditions are among the most frequent psychiatric disorders found in the non-disabled youth population. However, prevalence figures have varied considerably. Looking at

studies conducted over two decades, Cartwright-Hatton, McNicol and Doubleday (2006) found the prevalence of any anxiety disorder in children to range between 2.6% and 41.2%. More recent studies have found prevalence to range between 9% and 32% during childhood and adolescence (Creswell et al., 2014) and recent studies have tended to support these estimates (Asselmann & Beesdo-Baum, 2015; Garber & Weersing, 2010; Kendall et al., 2010).

The wide disparities in these figures may be due to the fact that studies have focused on children of different ages, the wide range of anxiety subtypes that exists, as well as the differences between global cultural settings and, as will be discussed, these variables have been found to mediate the severity of anxiety in children with ASD. They may also reflect a lack of clarification in diagnostic criteria and instruments and insufficient guidance on assessment provided in the manuals (Beesdo, Knappe, & Pine, 2009), as well as the fact that diagnostic tools have been revised over time. Assessments of anxiety in younger children may need to rely on the observations of third parties, such as parents, which add yet another element of variation to the findings.

2.2.2 Prevalence of anxiety in children with ASD

Studies by de Bruin, Ferdinand, Meesters, De Nijs and Verheji (2007) and Klin, Pauls, Schultz and Volkmar (2005) have shown that 50% of children with ASD are affected by comorbid anxiety disorders, although there is a wide variance in prevalence findings in this population as well. For example, studies using standard interview tools have found that anxiety disorders occur in over 30% of youth with ASD (De Bruin et al., 2007; Leyfer et al., 2006; Wood & Gadow, 2010).

White et al. (2009) conducted a review of 40 papers published between 1990 and 2008 (using the search terms ‘autism’, ‘Asperger(s)’ or ‘pervasive developmental disorder’ and ‘anxiety’ or ‘anxious’) and from their review of these papers, they found prevalence rates to range between 7% and 84%. A systematic review of 31 studies in the literature was also conducted by van Steensel, Bogels and Perrin (2011) which included 2121 young people with

ASD (under 18 years old) and demonstrated that around 40% of them had a minimum of one comorbid anxiety condition (van Steensel et al., 2011). Their research found that the most frequent type of anxiety was specific phobia, which manifests in 29.8% of young people with ASD, and thereafter OCD that affects around 18%, along with approximately 17% of social anxiety disorder.

Systematic reviews are useful because they enable conclusions to be drawn on the basis of a wide range of empirical findings, and comparisons may be drawn that take into account variations in the methodologies used by each individual study. This is particularly useful in the field of anxiety in children with ASD, given that there are varying levels of ASD severity and unique combinations of comorbid disorders. However, since the findings have a wide range, as in the study conducted by White et al. (2009), it is questionable how useful such studies are to identify prevalence. What such reviews do show is the lack of standardisation in measuring tools and that exact prevalence rates remain unclear. The wide discrepancies suggest that substantial difficulties arise when attempting to identify anxiety when it is comorbid with ASD. This is probably due to the overlap in symptoms and neurology and it is important that these overlaps are taken into account when these separate disorders are diagnosed. Reports of anxiety within the ASD population have also varied due to differences in age and identity of the informant (for example, whether it is a parent or child) (Van Steensel et al., 2011).

Difficulties in measuring anxiety when it occurs with ASD may also be due to the fact that both disorders manifest at different levels of severity and the wide variations of subgroups within both spectrums compound the difficulties in distinguishing the disorders. Indeed, anxiety is considered, "sufficiently inherent to ASD" that the DSM-IV has recommended that further diagnoses of certain anxiety-based conditions are required ''to be not better accounted for by the ASD itself'' (Van Steensel et al., 2011, p.302). Van Steensel et al. (2011) left open the question whether anxiety could be considered as an element of the wider ASD-phenotype and other scholars have agreed there is still uncertainty as to whether anxiety reflects the core

features of ASD or is rather a separate condition (Williams, Leader, Mannion, & Chen, 2015), which is still a very controversial issue.

Anxiety forms a key part of this study's area of focus and is discussed in greater depth in the following sections. The first section will begin by discussing anxiety in TD children, in order to gain an understanding of anxiety in the general population. It then examines the interplay between the disorders when anxiety occurs in an individual with ASD.

2.3 Explanations of anxiety in typically developing children

Research has investigated the aetiology of childhood anxiety from various angles and a wide range of factors have been implicated as causal to the disorder. Research is increasingly drawing towards the conclusion that factors combine to cause anxiety throughout childhood and adolescence (Muris, van Brakel, Arntz, & Schouten, 2011). According to Muris (2003), these factors include inherited genetic traits predisposing to the characteristic, the inability to regulate emotions, the types of parental practices, and environmental or educational conditioning. The impact of genetic factors on anxiety has been well-researched and studies on monozygotic and dizygotic twins have indicated various sub-types of anxiety to be hereditary (with anxiety being higher in monozygotic than dizygotic twins) and several genetic aspects were recognized (Al-Biltagi & Sarhan, 2016).

The following section will discuss a number of common explanations for anxiety, covering a number of angles including psychological, behavioural and genetic models. The causes of anxiety will be discussed in terms of environmental learning pathway models, parental factors, individual factors and, finally, genetic variables.

2.3.1 Environmental learning pathways

In terms of psychological and behavioural theories, Rachman's three pathways theory (1977) argues that anxiety can develop as the result of firstly, direct learning experience, secondly, through vicarious learning (that is, observing the fearful response of another person to a stimulus); or thirdly, through verbal threat information (Muris & Field, 2010). Rachman's

theory indicates that anxiety is a disorder that is learned cognitively through experience and this is supported by Muris and Field's (2010) review of three decades of research using experimental studies, as well as quantitative and qualitative research on children's and parents' perspectives. Other research has conceptualised anxiety as an intolerance of distress (McHugh & Otto, 2011) and this can lead to impulsive/avoidance behaviours, which can themselves elevate levels of anxiety (McHugh & Otto, 2012).

2.3.2 Parental factors

Some research has covered the importance of psychological relationship variables between parents and children in the development and maintenance of childhood anxiety (Lazarus et al., 2016; McAdams et al., 2015). Parenting is an interaction and therefore the influences of both parent and child with ASD will affect the development of the familial relationship (Brooker et al., 2015; Hinshaw, 2008; Lavigne, Hopkins, Gouze, & Bryant, 2014). Parental influence is important, however, because the child with ASD requires a significantly greater degree of parental guidance and support and children are sensitive to the responses and behaviours of their parents. For example, parents may influence their children's behaviour through modelling. Where a parent demonstrates anxious responses, a child is more likely to learn these behaviours when faced with a stressful situation (Wood, McLeod, Sigman, Hwang, & Chu, 2013). In this respect, some research has indicated that maternal anxiety is highly influential on child anxiety, although paternal anxiety is less significant (Coric, Banozic, Klaric, Vukojevic, & Puljak, 2014).

There are various ways in which a parent can influence their child's levels of anxiety. For example, in addition to the modelling theory described by Rachman, parental influence on child anxiety has often been explained in terms of parental acceptance (or rejection) and the psychological effects of granting autonomy (or enforcing control). Acceptance refers to the interactivity between parent and child and the degree of sensitivity towards the child's needs, such as active praise or reassurance (Wood et al., 2013). It is suggested that parents who respond

to children's expressions of insecurity help regulate their emotions and build tolerance to negative affect (Davidov & Grusec, 2006).

An examination of the Parental Acceptance-Rejection Theory (PARTheory) across cultures has suggested this may manifest in cold and unaffectionate behaviours, hostility, or aggression, or neglect (Rohner, Khaleque, & Cournoyer, 2012). Therefore, parental rejection is assumed to increase anxiety because it involves decreased levels of warmth, sensitivity and approval (McLeod, Wood, & Weisz, 2007). The granting of autonomy is seen as the opposite of parental control (Mattanah, 2001).

Much current research on child anxiety has focused on maternal over-involvement or over-control (Lazarus et al., 2016) and studies suggest that maternal drives for 'perfectionism' can be an influential variable which, when combined with over-control, can be a significant mediator for child anxiety (Affrunti & Woodruff-Borden, 2015). This may be explained by the psychological pressures of parental expectations but also the possibility of a fear of corporal punishment (Graham & Weems, 2015). To date there has been less research on the influence of paternal control, although the research that exists suggests this can also operate as a factor (Greco & Morris, 2002). It is speculated that the underlying fear of corporal punishment may be greater when paternal control is in issue.

Studies have also researched the impact of a child's anxiety upon their parent's mental health (Hastings & Brown, 2002) and have shown that parental control can change as the child grows older (Freeman & Newland, 2002); shyness in infancy may predict greater levels of parental involvement in the future (Rubin, Coplan, & Bowker, 2009), but increased parental overprotection can also cause internalising problems for children later in life (Bayer, Sanson, & Hemphill, 2006). These findings support the notion that anxiety is part of a bidirectional process that can occur between a child and their external environment (Hinshaw, 2008; Lavigne et al., 2014).

It is interesting to note that some children may interpret parental responses differently, meaning that while observers may identify some behaviours as hostile, the child themselves

may not feel rejected in practice. Indeed, studies have found significant variations in parenting styles across the world, with some countries taking a stricter view of appropriate parenting behaviour as a matter of accepted cultural standards (Lansford & Bornstein, 2011; Lansford & Deater-Deckard, 2012). This has led Kagan (1978, p.61) to suggest, "parental rejection is not a specific set of actions by parents but a belief held by the child". What is clear is that the influence of parents is significant and this is a central feature of the present research design.

2.3.3 Individual factors

Various factors for childhood anxiety have been identified, including a child's personal temperament (Schwartz, Snidman, & Kagan, 1999; Degnan, Almas, & Fox, 2010). Research also shows that the age of the child is important where anxiety in TD children is concerned. For example, studies have found that the focus of the anxiety often changes as the child matures; whereas 6-7 year olds tend to be anxious about supernatural beings, physical harm or the dark, 8-9 year olds are more concerned with failure, being humiliated or disagreement between their parents. 11-13 year olds report feeling anxious about being strange or different to their peers, losing their possessions, or being fooled by others (King, Hampton, Strommen, & Fraser, 2014). Children may therefore exhibit different levels of anxiety at different ages, which may also reflect the environmental exposures expected of their age, such as the level of their educational institution.

2.3.4 Genetic variables

Current thinking is that there is gene–environment interaction and that individuals may carry genetic vulnerabilities that make them more susceptible to be effected by an environmental stressor (Hudson et al., 2013), although these genetic vulnerabilities may be successfully mediated where there is sufficient social support available to the individual (Belsky & Pluess, 2009). Hudson et al. (2013) suggest this reflects the fact that individuals will differ in terms of the benefit they can receive from environmental sources of support.

As such, genetic dispositions could possibly interact with ecological elements to encourage the onset of anxiety and this is likely, given that both these factors have been found to be influential in separate studies (Bogels & Brechman-Toussaint, 2006; Ellis, Boyce, Belsky, Bakermans-Kranenburg, & van Ijzendoorn, 2011). While important to the aetiology of ASD, the present study will not be examining the genetic data of the participants. It will however assemble some demographic information about their ethnicity.

2.4 Explanations of anxiety in children with ASD

The aetiology of anxiety in ASD is distinctive from the TD population because the ASD disability itself triggers various cognitive and behavioural responses, which are similar in nature to anxiety responses (Van Steensel et al., 2011). As such, models of anxiety in ASD put forward include both cognitive and behavioural bases (such as parental modelling), but also genetic and neurodevelopmental ones. Research demonstrates that anxiety occurs more often for young people with ASD than TD children (Guttmann-Steinmetz, Gadow, DeVincent, & Crowell, 2010; Williams et al., 2015).

2.4.1 Models of anxiety in ASD

Research has considered that it is possible for anxiety symptoms to be a 'proxy for core ASD symptoms' although the psychometric and genetic research suggests it is unlikely that anxious behaviours are only due to ASD and not to underlying mood dysregulation as well (Wood & Gadow, 2011). In Figure 1, p. 29, Wood and Gadow demonstrate how ASD symptoms could lead to additional stress, as other individuals can find their behaviours inappropriate (Goodwin, Groden, Velicer, & Diller, 2007): for example, teachers who try to discipline a poorly behaving child with ASD, or negative responses that a child with ASD may get from peers.

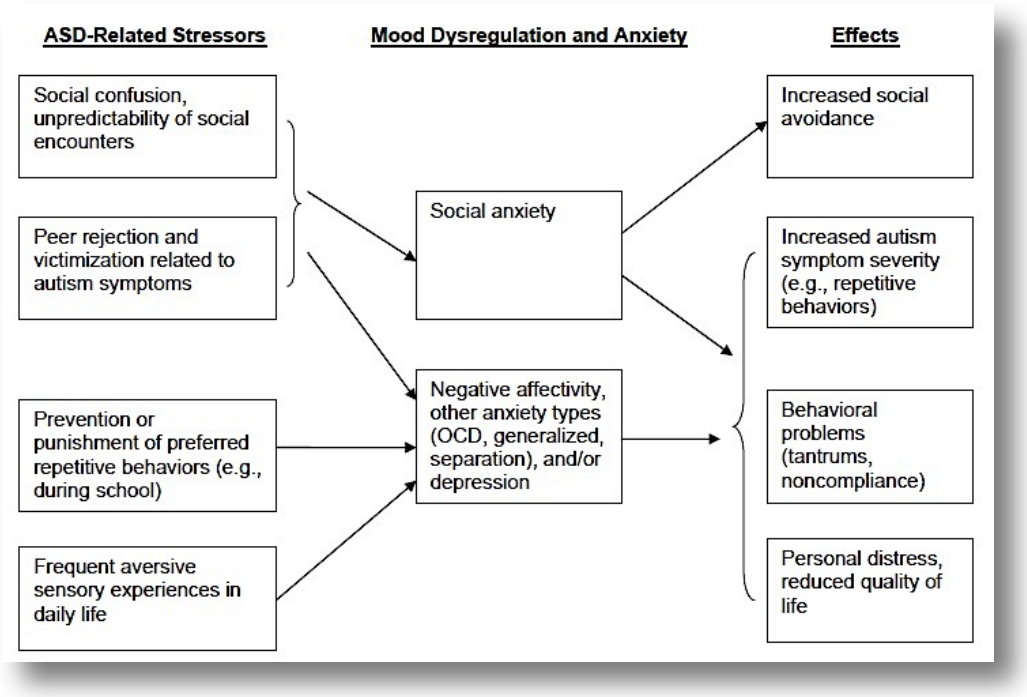


Fig 2.1: Hypothetical model of clinical anxiety in Autism Spectrum Disorders (Wood & Gadow, 2011, 287).

According to Wood and Gadow, stressful feedback that results from the ASD symptomology could either increase global negative affectivity, which is itself a risk factor for developing an anxiety disorder, or develop into a specific focus of anxiety, due to processes of repetition and learning. Heightened anxiety itself can impair functioning and as such, this stress may operate as a factor that reduces functioning in areas that were already impaired by the ASD.

The model proposed by Wood and Gadow (2011, p.287) is useful because it illustrates the dynamic processes of influence that occur as an individual with ASD interacts with the social environment. Where anxiety is not universally present in ASD, questions are raised as to how the development of anxiety can be prevented in these individuals. As this discussion has suggested, individuals with ASD could possibly be prone to have a separate condition of anxiety as a result of the challenges that the ASD disability creates. If phenotypically anxious behaviours are not a core symptom of ASD, there is greater hope for avoiding or reducing the development of anxiety in individuals with ASD.

Chalfant (2011) suggests that anxiety is provoked in children with ASD on the basis of the WCC or local/global processing theories developed by Happé and Frith (2006). As was discussed in the previous chapter, the WCC suggests this is a typical neurodevelopmental feature of ASD and this suggests that anxiety is more likely to be an inherent feature of neurocognition for these individuals. Given the pathological nature of local processing in ASD, they may find it more difficult to identify global reassuring cues, suggesting that individuals with ASD may have an underlying tendency to experience anxiety. Poor EF was recently shown to be related to greater rates of anxiety in adolescents with ASD (Hollocks et al., 2013). As discussed, attentional bias has been subject to exploration in various studies of anxiety, which have consistently found threat-related thoughts to be a result of the thought processes of anxiety-prone individuals (Cocia, Uscatescu, & Rusu, 2012; Field, 2006). Hollocks et al. (2013) studied the phenomenon of attentional bias in children with ASD. They employed images of emotional faces, which they coupled with emotional words. Contrary to their predictions, they found there was no difference in dot probe and anxiety scores between an ASD and non-ASD groups of participants.

The researchers suggest that this could be due to the fact that previous studies only found attentional bias in participants with more severe levels of anxiety although they did report that they found similar results when they split participants according to the severity of their anxiety levels. The authors also suggest the ambiguity is compounded by the lack of empirical research examining the cognitive correlates of anxiety in ASD.

Other studies (Evans, Canavera, Kleinpeter, Maccubbin, & Taga, 2005) have suggested that anxiety in children with ASD is prompted through ASD-specific behavioural patterns, such as a higher predisposition to self-accountability, lower coping potential and a lower future expectancy capability (Sharma, Woolfson, & Hunter, 2014). The authors stated these findings were based on an early study by Smith and Lazarus (1993), which posited that individuals assess their ability to change or influence difficult situations, as well as their emotional ability to deal with them, although the latter study was conducted on the adult population and not on children

in particular, nor on individuals who had ASD. People who conclude they are not able to cope with a situation may experience negative feelings. They may also assess the likelihood that there will be a positive or negative outcome following a particular event. Self-accountability refers to the degree of personal responsibility a person assumes when dealing with a particular event, which may include feelings of guilt (Sharma et al., 2014).

Other studies have suggested alternative analyses, such as that the problem lies either in overestimating the nature of threat or underestimating their ability to deal with it (Sharma et al., 2014). Children with ASD are more likely to find the cognitive processing of these experiences difficult, both because children often have a less developed view of the outside world than adults, but also because ASD is hallmarked by problems in perception of the external environment (Gaigg, 2012).

2.5 Differences between anxiety in TD children and children with ASD

Research has indicated that children with ASD very often have higher levels of anxiety than TD children (Cagetti et al., 2015; Grondhuis & Aman, 2012; Mayes et al., 2012) and comorbidity with ASD can significantly increase the difficulty that individuals with ASD experience. Farrugia and Hudson (2006) showed that both ASD and TD children with anxiety experience automatic negative thoughts, although individuals with ASD have higher levels.

Further, while anxiety symptoms may appear similar, the underlying reasons for these behavioural responses may be different. Children with ASD may also have a greater tendency to experience the physiological symptoms of anxiety, given that sensations are often felt more acutely in the body (Brosschot, 2002; Chalfant, 2011). ASD also makes it more difficult to regulate arousal, leading to a reduced ability to respond to and cope with stress (Bellini, 2006).

In their study, Evans et al. (2005) found that children with ASD were more likely to have phobias about particular situations and medical treatment, yet fewer concerns about harm or injury than TD children. Anxieties were also more likely to be followed by challenging behavioural responses in children with ASD than in TD children, and they considered ASD to be the causal variable, where mental and chronological age were matched.

In summary, anxiety can exist in numerous forms as well as differing levels of severity and it is a significant challenge for many children and adolescents. While anxiety is clearly more significant in those with ASD as opposed to TD, it is not universal in ASD and this suggests that anxiety exists as a separate pathology in these individuals. Anxiety is caused by multiple genetic interactions: interpersonal and individual elements, including parenting. In the next section, the focus shifts to the phenomenon of dental anxiety. The following sections will discuss dental anxiety in TD children and children with ASD. After some introductory remarks, the prevalence of dental anxiety in both groups is outlined, and factors that affect the development of dental anxiety in TD children and children with ASD are explored. The chapter will end with a brief description of the interventions used with dentally anxious patients before describing the aims of the thesis.

2.6 Dental anxiety

Dental anxiety, or dental fear, simply refers to heightened nervousness regarding the receipt of dental care and has been defined as "a feeling that something dreadful is going to happen in relation to dental treatment" (Blomqvist et al., 2014, p.1). In this respect, Klingberg and Broberg (2007) distinguish between 'dental fear', which they describe as a 'normal' response to specific threatening stimuli, 'dental anxiety', which is a state of apprehension that a negative experience will occur and 'dental phobia', which reflects severe and persistent anxiety in relation either a particular situation, or object, or towards the dental visit in general. Dental anxieties are problematic because they can lead to individuals avoiding dental treatment and having a poorer standard of oral health (Lu et al., 2013; McKinney et al., 2014).

2.7 Prevalence of dental anxiety

2.7.1 Prevalence of dental anxiety in TD children

Studies have shown the global prevalence of dental anxiety among children in the TD population to be somewhere between 5% and 20% (Paryab & Hosseinbor, 2013). Some studies have noted differences in prevalence rates due to geographical location and some European

studies have shown prevalence to be 5.7% for 6-8-year-old children (Elberling et al., 2015), while rates have been measured as high as 41.1% for children living in northern Brazil (Soares, Lima, Gomes de Barros, & Colares, 2014). These suggest cultural factors may operate in the development of childhood anxiety (such as cultural attitudes to stressful situations or willingness to express feelings of stress when in an interview), but may also reflect different measuring tools applied or even differences in language, where the same tool expressed in a different language may lead to different responses from participants.

2.7.2 Prevalence of dental anxiety in children with ASD

No studies were located that report precise prevalence statistics for children with ASD, although Lai et al. (2012) contend these rates are likely to be higher than those in TD children due to their already high incidence of anxiety. Research indicates that as many as 75% of the adult population are believed to have some level of dental fear and that around 11% have a high level of dental anxiety (Humphris & King, 2011) and, as such, it can be estimated that the prevalence of dental fear in children with ASD is high.

2.8 Factors that affect the development of dental anxiety in TD children

The causes, predictors and mediators for dental anxiety have been widely researched in TD children. A number of cognitive behavioural explanations exist, such as the individual's perception of their oral health and how they subsequently behave around the dentist and colleagues, but also intrinsic factors, such as their gender and age, as well as environmental factors, such as socioeconomic status and social isolation (Stein et al., 2014). In addition, genetic explanations have been put forward. The evaluation of dental anxiety can be problematic for methodological reasons, including the inherent biases involved in self-report surveys, views of self-confidence affecting the way people rate themselves, and lack of honesty about weaknesses (Möricke, Buitelaar, & Rommelse, 2016). The present section will go on to discuss a number of the variables discussed in the literature.

Amongst TD children, dental anxiety can be prompted by the perceived implications of bad oral hygiene (Carrillo-Diaz, et al., 2012) and, similarly to adults, to the perceived threat of pain and trauma (Townend, Dimigen, & Fung, 2000). Children may be at a greater risk of dental anxiety than adults, when meeting unfamiliar adults at the surgery, as well as the unusual sounds and tastes involved, in addition to having to modify their physical behaviour, such as by lying down and remaining still (Paryab & Hosseinbor, 2013).

2.8.1 Oral health status

Goettems, Ardenghi, Romano, Demarco and Torriani (2011) also reported that poor oral health and the presence of dental caries are closely related to dental anxiety. It is mentioned that the children evaluated in this study were from Brazil and it is reported that children from this country are less likely than children from other countries to visit the dentist routinely and as recommended (they are more likely to attend where there is pain or accidental injury only) (Kramer et al., 2008). Carrillo-Diaz et al. (2012) proposed a model to help conceptualise the experience of dental anxiety in children. Their study drew on a sample of over 160 children, which included females and males from 7-14 years old. Bivariate correlations and hierarchical regression analyses were used to demonstrate that children's subjective oral health status and their perceptions of vulnerability were strong predictors of dental anxiety. Specifically, these authors sought to determine the relationship between oral health status, perceptions of cognitive vulnerability and the experience of dental anxiety. In Figure 2, the authors describe the circular relationship between these variables.

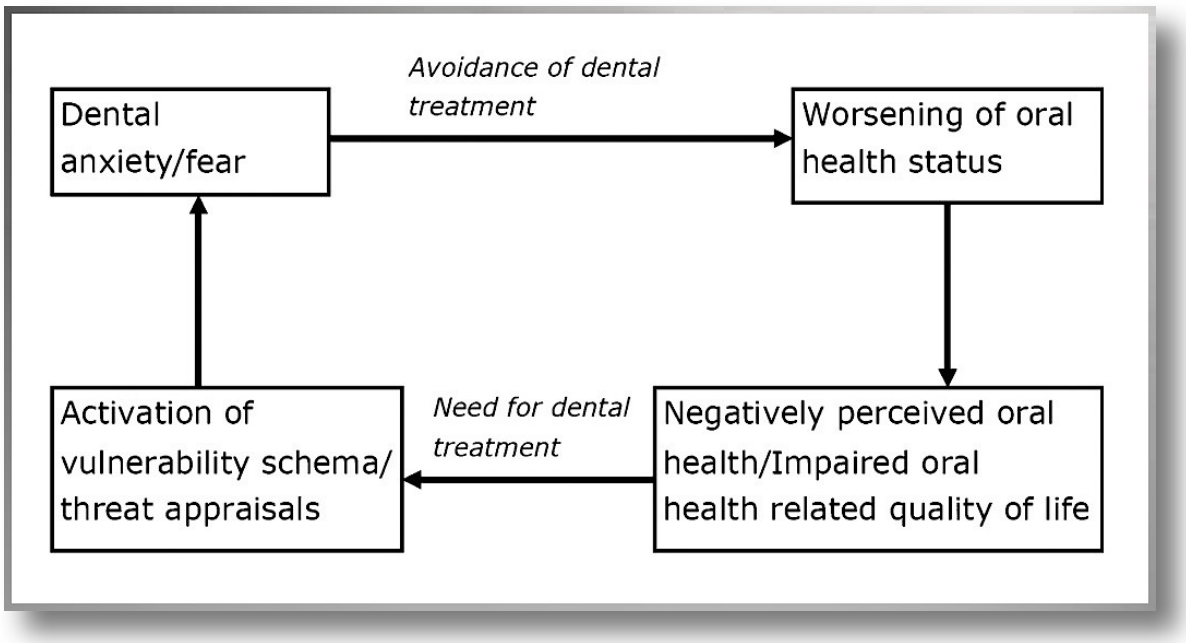


Fig. 2.2: "Circular relationships among dental anxiety, oral health status, subjective oral health and cognitive vulnerability/appraisals" (Carrillo-Diaz et al, 2012, pg.10).

This model is based on three hypotheses: that juvenile dental fear is associated with self-perceived oral health status; that those who consider their oral health to be poor will experience higher levels of anxiety; and that cognitive vulnerability, which holds that patients will not be able to control or predict treatment that is considered unpleasant, will mediate the relationship between negative oral health-related evaluations and dental anxiety in children. In their study, the authors discuss the concept of 'dental pessimism' (Wardle, 1984), which describes the informational processing biases associated with anxiety as previously discussed.

The authors predicted a 'vicious circle' dynamic, where dental fear leads to the avoidance of dental visits and therefore a reduction in oral health status, leading to increased anxiety and the continuation of the avoidance pattern. This theory is put forward on the basis that mental health disorders are more likely to affect the seeking of treatment and may also increase the risk of needing dental treatment in the first place. For example, where an individual avoids going for check-ups, they may be at risk of problems becoming worse over time, leading to a need for more invasive treatment (Carrillo-Diaz et al., 2012). The results of their research suggest that the children in the sample evaluated their oral health status accurately and confirmed the

authors' predictions (Carrillo-Diaz et al., 2012). This also confirms previous research (Armfield, 2010; Gisler, Bassetti, Maricske-Stern, Bayer, & Enkling, 2012) about the relationship between a loss of control, oral health, and anxiety. It is clear that cognitive vulnerability and oral health are key mediating variables in the occurrence of dental anxiety, and these factors represent critical focal points for psychologists and dentists seeking to reduce fear in children (Carrillo-Diaz et al., 2012). Their concept of cognitive vulnerability makes use of Armfield's (2006) approach, which explored the acquisition of fears and specific phobias related to an area of anxiety (such as dental anxiety).

Based on existing research identifying dangerousness, disgustingness, unpredictability, and uncontrollability as ways to classify fears, Armfield (2006) suggested these form a framework of beliefs through which a person perceives stimuli or situations.

2.8.2 Gender

Gender differences have also been recognised in the factors affecting dental anxiety, namely that there were more positive correlations between low levels of oral hygiene and emotional well-being among girls than boys (Carrillo-Diaz, Crego, & Romero-Maroto, 2013). The study by Salem, Kousha, Anissian and Shahabo (2012) also found that dental fear and anxiety was more prevalent in girls than boys, although they explained the differences as possibly due to socialisation norms. Such findings have been supported by other research (Klingberg & Broberg, 2007). Other research has also found low levels of oral hygiene and emotional well-being in TD children to be more prevalent amongst girls than boys (Carrillo-Diaz et al., 2013) and research suggests girls are more predisposed to dental anxiety than boys (Alaki, Alotaibi, Almabadi, & Alanquri, 2012; Taani, El-Qaderi, & Abu Alhaija, 2005).

2.8.3 Age

The Salem, Kousha, Anissian and Shahabo (2012) study found dental anxiety was significantly correlated to age and that children of 3-4 years of age manifested the lowest levels of fear, which the authors consider may be due to their lack of cognitive maturity and, therefore,

of awareness of what is taking place. It is reported that this study only examined children aged 3-6 (and, as such, children who were older were not included). Klingberg and Broberg's (2007) meta-analysis of papers found that age was not uniformly considered as causal although that study was limited by the fact that it relied on publications from one database alone and this may have meant some relevant findings were omitted from the review. In terms of age, older children may develop greater familiarity with dental treatment than younger children, who may be more likely to manifest behavioural problems. In this respect, Bessadet, Collado, Carrasco, Rogerleroi and Hennequin (2010) found that the age at which a child is first introduced to a dentist is a factor affecting the degree of anxiety they experience.

The study by Alaki et al. (2012) was one of the few studies conducted in Saudi Arabia and the authors noted that the prevalence of dental anxiety is higher in that country than in many others. They suggested that this was due to the fact that children in Saudi Arabia are less likely to be exposed to dentistry at an early age, which can help to reduce dental anxiety. Different parenting styles, according to cultural norms, may affect attitudes towards the maintenance of dental health (Ng, Demopoulos, Mobley, & Ditmyer, 2013). Age dependent correlations with dental anxiety have been consistently reported (Appukuttan, Tadepalli, Cholan, Subramanian, & Vinayagavel, 2013).

2.8.4 Socioeconomic status

Socioeconomic status may also affect dental fear. For example, children from lower socio-economic backgrounds may be less likely to visit the dentist regularly (Carrillo-Diaz, Crego, Armfield, & Romero, 2013). A study by Oliviera and Colares (2009) relied on parental self-report measures and found family income was directly related to dental anxiety ratings. Poorer children have a higher incidence of caries, which leads to both physical pain but also adverse social consequences, as they feel ashamed about smiling and may even stop playing with other children (Oliviera & Colares, 2009). These findings are supported by research by Alaki et al. (2012), which found that caregivers of children in private schools were more aware

of oral health than those of children in public schools. Children from private schools also had less complex dental needs and their needs involved less invasive procedures.

2.8.5 Pain and the dental environment

Previous research has mentioned the role of the child's perception of pain on dental anxiety. An interesting study was conducted with a Brazilian group of 167 children aged 8-11 years for a period of six weeks, during which time they went to a dentist once a week (Ramos-Jorge et al., 2013). The sample was selected from a group of children who were waiting for treatment. The sample was divided into two groups: children with toothache and children without toothache. Levels of anxiety were assessed throughout the treatment using the modified Venham Picture Test (VPT). The results showed a significant decrease in both groups (with and without toothache). However, at the initial visit children with toothache had significantly higher levels of dental anxiety than children who had no toothache (Ramos-Jorge et al., 2013).

This study underscores the degree to which pain contributes to dental anxiety and such findings have been confirmed by other studies (Oliviera & Colares, 2009). As the authors note, however, the study by Ramos-Jorge et al. (2013) only measured children with low to moderate levels of anxiety and therefore did not include children with high levels of anxiety who, according to their findings, would probably have higher levels of anxiety related to dental pain.

2.8.6 Genetics

There is evidence (Goettems et al., 2011) to suggest that dental anxiety has a familial component which may be either genetic or due to socialisation. It is likely that genetically inherited anxiety will be general in nature and therefore be in accordance with the findings on anxiety and genetics as discussed thus far, whereas anxious responses learnt through socialisation may well be due to modelling as a result of parents' demonstrated anxiety towards dental visits.

2.9 Factors that affecting that development of dental anxiety in children with ASD

An individual with both anxiety and ASD has a significant level of cognitive disadvantage which operates to make social interaction within the wider environment more challenging, and which may itself then affect neurological and biochemical responses. As such, the genetic make-up, personality and life experiences of an individual are likely to determine their level of dental anxiety (Silva et al., 2013). For example, regardless of heredity, two monozygotic twins may have different experiences in the dentist surgery in practice and, through behavioural learning, may develop very different levels of dental anxiety. The current literature in this field is limited, so the present research may contribute to current understanding.

Factors that have been found to affect the development of dental anxiety in TD children have not been widely researched in children with ASD. However, some factors have been explored in depth, such as sensory sensitivities and social communication.

2.9.1 Sensory processing sensitivity

One of the most widely accepted theories to explain the difficulties children with ASD experience with home-based and professional oral care is sensory processing (Stein, Polido, Mailloux, Coleman, & Cermak, 2011). Research into the sensory processing of individuals with ASD suggests that such children have a different response than TD children (Kuhaneck & Chisholm, 2012). This research stems from Kanner's (1943) early observations that children with ASD can have particular fears of noises, or interest in things such as lights switching on and off. Unusual responses to sensation can serve as a barrier to dental visits and make treatment difficult to administer.

It is recognised that children with ASD exhibit co-occurring sensory processing problems, and previous literature has noted the prevalence of sensory difficulties in children with ASD to be up to 80% (Ben-Sasson et al., 2009). Children with ASD may display either intense or low-reactivity to sensory stimuli and this tends to produce undesirable responses, such as distress or avoidance (Mazurek et al., 2012). Oral sensitivity may cause a physical

reaction of avoidance (Stein et al., 2011), as seen in approximately 50% of children with ASD (DeMattei et al., 2007). Additionally, in a busy surgery, the level of noise may be very distracting and overwhelming (Shapiro, Sgan- Cohen, Parush, & Melmed, 2009) and the lighting may cause squinting (Tomchek & Dunn, 2007). Sensorily adapted environments can reduce anxiety levels through reduced lighting, rhythmic music, a deep pressure chair and child participation tailored to the child's individual comfort needs (Loo et al., 2009).

In a questionnaire study answered by parents of 206 children with ASD, Stein et al. (2011) confirmed that children with ASD experience greater levels of sensory sensitivities and behavioural problems, which parents claimed hindered their child's oral health care. In that study, surveys administered to parents asked questions about tooth-brushing practices at home, experiences during routine dental care and sensory issues they had noticed in their children, such as a dislike of bright lights and loud sounds (Stein et al., 2011). These questionnaires were presented to parents for their opinions on their child's emotional state.

Of course, these results were based on the parent's opinion and did not examine anxiety in a clinical setting. This method did however permit the study to consider how anxiety occurred in a more holistic way, as the parents were able to comment on the child's anxiety both at the dentist as well as at home. Stein, Polido and Cermak (2013) further investigated this relationship in a questionnaire study of 396 parents of TD children and children with ASD. Children with ASD generally had greater sensory over-responsivity than TD children; among children with ASD, those who had the highest levels of sensory over-responsivity also had greater oral care difficulties during both home and office oral care.

Overall, children with ASD scored significantly lower than TD children on expressive language ability, and significantly higher on screening measures for sensory processing difficulties (SSP), general anxiety (CASI-Anx), and dental anxiety (CFSS-DS); during the cleaning they exhibited significantly higher levels of overt behavioural distress, uncooperative behaviour and requirements for restraint (Stein, Lane, Williams, Dawson, Polido, & Cermak, 2014). Behavioural difficulties were also correlated with linguistic communication ability,

where poorer communication resulted in more behavioural problems (Stein et al., 2014). Physiological levels of anxiety were higher for children with ASD, especially during fluoride application; these levels of anxiety were correlated with behavioural distress for children with ASD, whereas a relationship between age and behavioural distress in TD children was found (Stein et al., 2014).

The addition of physiological measures may be considered a strength of the Stein et al. (2014) study, as the authors were able to compare these findings with psychological, behavioural findings. A further strength is that the study was completed in the clinical setting. Increasing age was also associated with improved behaviour for TD children but not for children with ASD, suggesting that TD children are able to learn effective coping behaviours over time, while children with ASD manifest delayed learning abilities (Stein et al., 2014).

By including patients undergoing the same type of treatment (routine cleanings), the authors were able to incorporate an important degree of standardisation in their analysis, since each patient would be receiving the same treatment, which was also minimally invasive compared to more traditionally painful procedures (Stein et al., 2014). Standardisation also resulted from the fact that all the sample were recruited from the same surgery, meaning the dental staff, equipment and working practices would have been the same for each patient.

However, this clinic specialised in treating disabled patients in general and this may have made the staff more aware of how to treat patients with ASD. The study may also have been limited by its sample size (consisting of only 44 children) and as the authors themselves point out, some of the variations within the autistic spectrum may not have been represented proportionately. They recognise that the majority of their sample was low functioning, meaning their findings may not be automatically generalizable to children with HFA. The study may also have been limited by the fact that some of the sample had already participated in previous research studies at the clinic, which may have led to altered responses given their familiarity with the test setting (Stein et al., 2014). These variables could lead to individuals with ASD

experiencing a reduced sensation of anxiety and, as such, the results may not be fully generalizable, but they have the potential to point to good practice.

Although the Stein et al. (2014) study did not focus directly on techniques that can contribute to best practice, conclusions can be drawn from its findings in this respect. For example, given that the study found that children with ASD are more likely to display overt behavioural stress, measures for restraint were recognised as being necessary for effective treatment of some individuals in this group. The authors suggest additional staff members may be necessary to physically restrain those who are more distressed than others (2014). The study also found that the ASD group demonstrated greater NS-SCR frequency during certain stages of the visit than others (2014) and this suggests measures may be taken to target the aversive stimuli that are in play during those phases in particular.

Finally, the study also found that communication was a significant predictor of uncooperative behaviour (2014). The lower the skills of communication, the more likely problematic behaviours would manifest. This suggests that a core aspect of dental anxiety lies in the ability of the individual with ASD to receive and express information about the procedures and suggests that measures to overcome barriers to communication may have an indirect impact on the demonstration of behavioural resistance.

2.9.2 Social and communication deficits

Whereas there is a strong focus on sensory issues throughout the literature, only a few studies have looked at the child's anxiety over the dental environment due to social and communication deficits (Barbaresi, Katusic, & Voigt, 2006). The dentist and parent/s may need to use techniques tailored to the child's individual disability needs in order to engage him or her in the demonstration of the procedure (Delli et al., 2013). Although little current research has focused specifically on social and communication deficits as causes of dental anxiety, several behavioural management, social modelling and intervention studies have taken these

into account (Delli et al., 2013; Hernandez & Ikkanda, 2011; Isong et al., 2014; Iwata & Dozer, 2008; Lai et al., 2012).

Delli et al. (2013) reviewed the literature regarding the issues that arise when treating children with ASD. Their paper noted that the typical lack of curiosity for the external environment and the reduced ability to share information using verbal means can lead to problems when such children need to engage with dental staff. They suggested techniques to treat individuals with ASD which included communication strategies such as 'tell-show-do', the use of short and clear commands and differential verbal reinforcement.

Hernandez and Ikkanda (2011) also conducted a review of literature relating to behavioural management techniques. They described the use of 'voice-control' methods, supplemented by positive reinforcement, to direct children with ASD in an authoritative way. Despite recommending this method, the study recognised that some verbal statements can be ineffective where aversive stimuli in the surgery are too influential. Isong's (2014) study focused directly on the use of electronic screen media. It concluded that visual tools such as videos or movies can reduce fear and consequently uncooperative behaviours, due to the distraction these stimuli provide.

The paper by Iwata and Dozer (2008) examined the use of functional analysis as a tool to identify the reinforcers of problem behaviours for children with ASD in a dental setting. It identified the relationship between cause and effect and suggested that effective strategies must be able to compete successfully with reinforcers that increase problem behaviours. Finally, the study by Lai et al. (2012) conducted primary empirical research into unmet dental needs and the barriers to dental care. Their study found the behaviour of children with ASD to be a main barrier to successful treatment.

The current research does not collect extensive genetic information from the participants, nor does it examine physiological responses. It does, however, examine other factors that affect dental anxiety. As such, the present discussion has examined a number of causal variables that are identified in the literature. The present study examines the aetiology of dental anxiety in the

ASD population and the unclear overlap between these two disorders. This makes it difficult to speculate how relevant the anxiety variables that affect the TD population are to anxiety variables in the ASD population. From the material discussed, it appears they are two distinct disorders which share some common ground. The present study therefore recognises that some of the factors relevant to the TD population will also be relevant to the ASD population, and to dental anxiety in the ASD population.

2.10 Summary

The present chapter has considered the issue of dental anxiety by examining the phenomenon of anxiety as it arises in both TD children and children with ASD. Dental anxiety is a common problem for children and young people, which impacts on dental care and more widely on children's health. Causes of dental anxiety in typically developing children stem from an interplay of genetic factors, oral health status and cognitive behavioural factors, such as avoidance and threat interpretation. There is much less understanding of the reasons for dental anxiety in children with ASD, but sensory sensitivities and social communication issues undoubtedly play a part.

2.10.1 Aims of the thesis

This thesis seeks to advance our understanding of the factors associated with dental anxiety in ASD. This understanding will contribute to the development of theory and of causal models of anxiety in particular. Importantly, the research will also contribute to the development of effective interventions and good practice guides for children and adolescents with ASD.

The thesis consists of three studies. The first two are exploratory, 'bottom-up' studies that seek to identify relevant variables for later testing. The first study includes parents and individuals with ASD and the second involves a group of dentists with varying expertise in ASD. Although there is some knowledge now in the literature, there is a lack of research about ASD in this particular aspect. Also, very few researchers have consulted with individuals with ASD to ask them about their experiences. It is therefore intended to establish which factors may

be important by talking to those with ASD and to individuals closely involved in their care. This, in addition to findings from recent research and the information gathered from the first two studies, is then used to articulate the specific research questions and hypotheses that are tested in the third study. Broadly, the aim of this thesis is to understand the experience of dental anxiety in children and adolescents with ASD and to identify factors that might play a causal role in its development.

3 Chapter Three

Exploring Possible Reasons behind Dental Anxiety in Individuals with Autism Spectrum Disorders: A Qualitative Study

As described above, relatively little is known about the perceptions and experiences with dental care regarding of individuals with ASD. This qualitative study therefore set out with the aim of assessing the possible factors that affect dental anxiety in individuals with ASD and the techniques that they and their parents use to cope. Within a context of a potential rise in ASD prevalence (Matson et al., 2012), understanding dental fear and anxiety can help reduce barriers to appropriate treatment. Relatively uncomplicated strategies may be developed to meet these needs.

This qualitative study will examine the causes of dental anxiety in individuals with ASD and, once identified, the factors will eventually be examined further in greater depth through a statistical analysis. Therefore, the need for a bottom up approach was crucial in the development of this thesis. The following discussion will outline and consider the proposed methodology for this first, qualitative, phase, beginning with the strengths and weaknesses of qualitative research in general.

3.1 Qualitative research

Qualitative research has been defined by Howitt (2010) as analysis which is based upon rich textual, instead of numerical information. Qualitative research tends to focus less on achieving objective results and more on achieving insight into participants' perspectives, through its more personal and flexible methodology.

A constructivist paradigm is linked with interpretivism, which is generally an approach used in qualitative research (Creswell, 2009). The objective of an interpretive epistemology is to explore and recognize the ways individuals perceive their own world, and emphasises personal experiences (Smith & Osborn, 2003). This is very important for psychologists, or

teachers in the field of special needs, as it focuses research on the insights of individuals with special needs themselves (Avramidis & Smith, 1999). In their research, Avramidis and Smith argue that "the interpretivists intention is to offer understandings of the world, via qualitative methodologies, and reconstruct it where it exists" (p.28). Moreover, the constructivist approach is about the meanings and experiences that are constructed by people as they interact with the world (Creswell, 2009; Padgett, 2016). This method is determined by participants' views and experiences concerning a particular phenomenon (Creswell, 2009). Savin-Baden and Major (2013) note that constructivism considers that the person most knowledgeable about a particular phenomenon is the one who has experienced it.

One of the strengths of qualitative research methods is the ability to gather rich data and explanations (Castro, Kellison, Boyd, & Kopak, 2010; Silverman, 2016). In addition, the researcher spends considerable time and builds rapport with the participants, which adds value to the research (Creswell & Poth, 2017). Silverman (2016) notes that the qualitative interview helps the researcher to draw out information about the studied phenomena, which includes; people's insights about their social world, as well as the situation and background information from which the phenomena emerge. It is also that qualitative research has a tendency to offer much more depth concerning the individuality of those with disabilities, especially in relation to their condition, in comparison to that gained through quantitative studies (Avramidis & Smith, 1999).

However, qualitative methods have some weaknesses: for example, it is difficult to generalize the results to a wider community, and the research quality depends on the ability of the researcher to avoid bias (Bryman, 2012; Neergaard, Olesen, Andersen, & Sondergaard, 2009). Other weaknesses identified by Anderson (2010), relate to privacy and anonymity, and these may be evident in the presentation of results. In addition, science-oriented researchers sometimes find it difficult to understand and accept qualitative research (Anderson, 2010). The results of qualitative research take longer to assemble and are hard to display visually (Anderson, 2010; Gill, Stewart, Treasure, & Chadwick, 2008).

Qualitative research may therefore rely on open-ended interviews, participant observation, focus groups or other forms of in-depth encounters with participants, rather than impersonal questionnaires (Silverman, 2010).

Interviews can be structured, semi-structured or open-ended (Potter & Hepburn, 2005). In exploratory research, the most appropriate data collection method is open-ended or semi-structured interviews and these are often used to emphasise the perspectives of the interviewees and reduce the level of researcher bias (Silverman, 2010). The qualitative method used in this present study involved semi-structured interviews. The interviews were conducted with individuals with ASD who were anxious about receiving dental care, as well as with parents of individuals with ASD regarding their children's experiences.

An interpretivist epistemological position and a constructivist approach to the research methods is adopted in order to take account of the research aims and objectives. This study is focused on considering the personal experiences and thoughts of individuals with ASD and parents of individuals with ASD. The researcher's primary goal was to give the individuals with ASD and parents of individuals with ASD a voice, thereby making their thoughts, worries, and experiences heard. It is understood by the researcher that the participants are the most knowledgeable about the subject matter; their personal views, thoughts, and experiences of dental anxiety and how it effects their lives offer a unique, rich and immediate narrative for the research.

3.2 Research Questions

The research questions investigated in this study, from the perspective of people with ASD and parents, were as follows:

1. What are the common and general reasons that cause dental anxiety?
2. What techniques and strategies are used by individuals with ASD and/or their parents to cope with dental anxiety?

3.3 Methods

3.3.1 Sampling Procedure

It is, in most cases, impossible to carry out research on an entire population. Researchers therefore usually choose a sample of the overall population for data collection (Gilbert, 2008). For the purposes of this research, the sample chosen was young adults with ASD in Berkshire, in addition to parents of individuals with ASD in the same area.

A specific sampling approach was applied, which involved both purposive and convenience sampling (Denscombe, 2003; Silverman, 2010). Purposive sampling allows a researcher to target participants who are most likely to provide the required data and is considered the most suitable approach for qualitative research studies (Denscombe, 2003; Silverman, 2010). This study used purposive sampling for the recruitment of ten participants.

The sample was recruited through the Berkshire Autistic Society (BAS), which is an established charity providing comprehensive services in the Berkshire area for people of all ages with ASD, including their families, carers and professionals working in the field. In addition, word-of-mouth referrals and direct advertising were used, which helped to locate individuals to interview. Further contacts for interview were made through the researcher's attending of coffee mornings, local organisations for individuals with disabilities and ASD, such as Cerebra and various public talks on ASD by the researcher's supervisor. An advert was also placed on the Netmums.com online website about the study, and participants were recruited from the University of Reading student population. These locations were near to the researcher and convenient for sourcing the individuals with ASD.

3.3.2 Sample

Full researcher contact details were provided and those who responded were provided with further information. The targeted sample was made up of individuals with ASD and parent of individuals with ASD who met the following criteria below.

The criteria for individuals with ASD:

1. Adults with ASD who were over 18.
2. The individual with ASD must have verbal abilities and be capable of taking part in an interview.
3. Individuals with ASD should be able to understand and speak fluent English.
4. The individuals with ASD must have had some concerns about going to the dentist.

The criteria for parents of individuals with ASD:

1. Participants should be able to understand and speak fluent English.
2. For a parent of a child with ASD, their child must have demonstrated concerns about going to the dentist.

The reasoning behind the selection of the sample was to gain an in-depth understanding of participants' perceptions of their experiences in receiving dental care or their child's experience of receiving dental care in individuals with ASD who had concerns about receiving dental treatment.

T participants took part in the current study, six of them were parents of children with ASD and four were adults with ASD (Table 3.1, p.52).

Table 3.1: Participant Details

Participants	AGE	GENDER	ETHNICITY	DIAGNOSIS (Self-reported)
Participant 1 Adult with ASD	25	Male	British	Asperger's Syndrome
Participant 2 Adult with ASD	47	Male	Mixed Caucasian	Asperger's Syndrome
Participant 3 Adult with ASD	25	Female	Caucasian British	Asperger's syndrome
Participant 4 Adult with ASD	23	Female	Caucasian	Asperger's Syndrome
	Child's Age	**Child's Gender**	**Child's Ethnicity**	**Child's Diagnosis**
Participant 5 Mother	14	Male	British	Asperger's Syndrome
Participant 6 Mother	14	Male	White British	Autistic Spectrum Disorder
Participant 7 Mother	10	Male	White British	Asperger's Syndrome
Participant 8 Mother	13	Female	White British	Atypical Autism
Participant 9 Mother	11	Male	White British	Asperger's syndrome
Participant 10 Mother	13	Female	White British	Asperger's Syndrome

3.3.3 Ethical Approval and Consent

Ethical approval for the study was obtained from the University of Reading's Research Ethics Committee (Appendix 28, p.281). Each parent/guardian was asked to read an information leaflet outlining the study (Appendix 3, p. 227) and then sign a consent form. The consent form (Appendix 4, p.229) outlined the purpose of the study and its procedures and stated that his/her participation was voluntary and that they could withdraw from the study at any time. Parents signed the consent form for themselves. Adults with ASD, who were older than 18 years old and were capable of comprehending what they were being asked and were able to respond for themselves, were asked to sign their own consent form. The signed consent

forms were then stored in a locked cabinet and participants were given a duplicate signed copy of this consent form to keep.

Each participant had to sign a consent form, which stated that he/she had been given a copy of the participant information sheet, had been given the opportunity to ask any questions regarding the study and had been given a satisfactory answer. It also stated that the participant had been made aware that all personal information would remain confidential and that his/her participation was voluntary and that they could withdraw from the study at any time. In addition to getting written and verbal consent prior to interviewing, permissions were also obtained in relation to the audio-recording of the interview.

3.3.4 Data Collection

The main methodology used in this research was qualitative, semi-structured interviews, which allowed for a primary focus on the experiences of the participants. Personal interviews were conducted. The interviews focused on the participants' experiences with receiving dental care and their behaviours and thoughts toward receiving the care. The interview also focused on what coping strategies were used by the participants to manage their dental anxiety.

The semi-structured interview was used (Appendix 2. p.225) to guide the discussion, which allowed for an open discussion in some of the cases and allowed participants to include information that might not have been elicited by fully-structured questions (Holloway & Fullbrook, 2001).

3.3.5 Development of Interview Questions

The interviews with parents/guardians focused on their child with ASD and their dental fears. The interviews with individuals with ASD focused on their experiences at the dentist and their dental anxiety.

An interview schedule was developed based on the existing literature on dental anxiety, which had the limitation of being mostly related to TD children. In addition, several discussions were conducted with the researcher's supervisors, Dr Fiona Knott and Dr Tim Williams,

regarding the questions to be used in the interview. As the literature has demonstrated, research on dental anxiety in the ASD population is limited. In terms of dental anxiety, factors affecting the TD population include parental anxiety, previous negative experiences and cognitive appraisals, and these issues were included in the questions.

Given that the present study concerned individuals with ASD, the researcher was aware that specific considerations would be relevant to this population in particular. For example, as the literature has shown, individuals with ASD are more likely to suffer from problems with communication, whether that is understanding another person's point of view or putting the person's verbal communication into context, as well as enhanced sensory sensitivity (Kim et al., 2014). When creating the present interview schedule, the researcher looked to the factors that affect dental anxiety for children in general although the interview was intentionally simplified in order to meet the potential communication challenges in the ASD sample. The interview questions included examples, to make it easier for the participants to understand and further verbal clarification was provided during the discussions where necessary because the ASD participants sometimes demonstrated difficulties with understanding the questions.

A pilot interview was conducted with a 15-year-old adolescent with ASD to evaluate the interview questions and how easy it was for an adolescent with ASD to comprehend and respond to them. The pilot interview elicited a good response from the interviewee, who reported good understanding of the questions asked, but since the pilot interviewee was an adolescent some adjustments were made for interviews that would be conducted with older individuals.

3.3.6 Procedure

Once informed consent had been obtained, the interview sessions were initiated. Each interview lasted between 30 and 60 minutes. The interviews were conducted independently with either the individual with ASD or the parent of the individual with ASD and took place in a setting that was convenient for the participant. Interviews with the participants were audio-

recorded using a digital recorder and an application for recording on an iPhone, and the resulting files were transcribed into text files for data analysis.

The participants were interviewed individually and were given the choice of being interviewed either in a quiet, uninterrupted room located in the University of Reading, at their own home, or via Skype. It was considered that holding the interviews in a location convenient to the interviewee would help them feel at ease with the process. However, the researcher was aware that even planned events could affect stress levels in individuals with ASD. Interviews require respondents to think rapidly under pressure and interpret meanings behind questions (Howlin, 2004). The researcher was not a professional psychologist, nor had any particular training in communicating with people with ASD. This meant the researcher had to be extremely conscious of the interviewees' responses throughout the process, respond to their communication needs such as by pausing to allow them think, rewording the questions if they did not understand and giving them a break if they required one. The researcher also tried to make sure that the discussion remained calm and clear and that the interviewees did not lose concentration at any time.

After the interviews, the participants were thanked for taking part and the researcher instructed them as to how they could contact her if they had any further questions. Additionally, participants were asked if they would like to be contacted for future studies.

3.4 Data Analysis

Data analysis in qualitative research is an area of considerable controversy (Freeman, de Marrais, Preissle, Roulston, & St. Pierre, 2007; Silverman, 2010). This is partly due to the fact that the process of analysis involves cognitive and creative processes that are not easily reduced to sequences or stages, as may be the case with a quantitative design (Silverman, 2010). Unlike the scientific methods used in quantitative analysis, qualitative data analysis is a process that is dependent on the cognition of the researcher and the context.

The researcher has discussed anxiety, dental anxiety and the factors that affect their development in an earlier chapter (Chapter 2). In the analysis, these factors were considered

and therefore, the researcher adopted a deductive content analysis. A deductive analysis is carried out when a researcher looks at retesting existing data in a new context, which can be categories, concepts, models or hypotheses (Catanzaro, 1988; Marshall & Rossman, 1995).

In this research, the most common approach to data analysis was used, namely, thematic analysis. This requires a detailed analysis of themes that occur within the context of the research interviews. The initial element of this is a close reading of the transcripts of interviews (or other forms of data) to generate an initial five or six (or sometimes fewer) most commonly themes and then a re-reading of the data to identify all the places and contexts in which these themes occur (Howitt, 2010).

Thematic analysis identifies and describes patterns of meaning within the texts (Braun & Clarke, 2006). Patterns are defined as themes and a theme is described as that which "captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set" (Braun & Clarke, 2006, p.82). Braun and Clarke (2006) describe six phases of the analyses: a) getting familiar with the data, b) creating primary codes, c) looking for themes, d) assessing themes, e) labelling and describing the themes, and f) creating the report.

The thematic approach was adopted to guide the process of analysis. The researcher followed the six phases mentioned by Braun and Clarke (2006) and started by reading the transcripts a number of times, which made her familiar with the data (phase 1). Therefore, the data were analysed in the form of written text files. The text files were then read to find possible codes, using a pen to write a comment each time an idea occurred in the transcript (phase 2, see Appendix 5). The purpose of this coding is that it "reduces the amount of raw data to that which is relevant to the research question, breaks the data down to manageable sections, and takes researchers through the trans- formation of raw data to higher-level insights or abstractions as the development of the theme" (Vaismoradi, Jones, Turunen, & Snelgrove, 2016, p.104). The transcripts were then re-read and tagged with the initial codes using coloured markers representing each possible theme (Phase 3). The refining of themes involves reducing the data

into a more workable set of broader themes (Attride-Stirling, 2001) and allows a researcher to identify possible overlaps in the existing themes, which can allow new patterns and issues to emerge (phase 4). The labelling and describing of the themes is shown in Table 3.2, and constitutes phase 5 of the data analysis.

In the present study, the researcher started by breaking the data down into codes. She developed these codes by looking for distinct concepts and categories in her data, which will form the basic components of the analysis. The researcher used coloured markers to distinguish different concepts and categories (Appendix 6). For example, if interviewees consistently talked about parental dental anxiety, each time an interviewee mentioned a parent's dental anxiety, or something related to it, the researcher would use the same marker. At the end of each analysis the researcher ended with a transcript with different colours that highlight different codes. These were then grouped into themes.

The analysis of the data was conducted several times, which resulted in further editing and refinement of the results each time. Initially, five main themes were identified, based on the coding. From these, 33 sub-themes emerged (Table 3.2). The last analysis therefore added a further and more in-depth dimension to the study and findings.

3.4.1 Intercoder Reliability

As with both quantitative and qualitative data, reliability is an important aspect to consider in a research design (Campbell, Quincy, Osserman & Pedersen, 2013). Intercoder reliability concerns reproducibility by other people and describes procedures used to test whether different coders would code the collected data in the same way. Intercoder reliability, is the degree to which separate coders assess features of a transcript and achieve equivalent results (Tinsley & Weiss, 2000).

Qualitative responses are gathered from in-depth interviews, and these could have different meanings and are likely to lead to different analyses. Establishing intercoder reliability is difficult since the data is evaluated by different subjective researchers. The perspectives of

multiple coders can lead to insights to illustrate how objective the original researcher had been in terms of their qualitative data. Of course, even the reliability procedure is difficult, since coding is based on judgement and there is an absence of standardised measuring tools. The present study employed intercoder reliability to ensure that the interpretation was consistent.

The intercoder reliability procedure was carried out by dividing the transcripts into chunks. A chunk represented an idea or concept within the interview answer provided, which was then allocated to a broader theme. That is, the transcripts were not divided according to the original questions asked and answers provided, but rather those sections of the answers that represented a particular concept. Similar concepts were then grouped together under themes. These themes were identified by the researcher and agreed upon by the researcher's supervisor. One answer to a particular question may have been divided into more than one chunk. It was decided by the researcher and her supervisor that two different transcripts would be coded, representing 18% of the sample. One transcript was from a parent of a child with ASD and one from an individual with ASD. The transcripts were coded independently by the researcher and one of her supervisors.

It is noted, however, that while many qualitative studies employ methods of intercoder reliability, not many discuss the methods they use to assess the reliability of the findings (Campbell et al., 2013). Intercoder reliability generally requires two or more equally capable coders working independently to identify the same code for the same unit of text (Popping, 2010). A method described by Campbell et al. (2013) involved one random transcript being selected for coding by two independent people out of a total number of approximately 100 interview transcripts. In his article, Krippendorff (2011) gives the example of testing three sets of data out of a total of one hundred. Other studies have simply suggested that the multiple coders rely on "a small set of documents" (Grimmer, King & Superti, 2015). As such, it is suggested that the present study took further measures than is usual to assess reliability.

The sample that was chosen for the intercoder reliability was chosen randomly and reflected both types of transcripts collected by the present research, namely that of a parent of

a child with ASD and also an individual with ASD. The percentages were calculated at 83% (reflecting 15/18 agreement and 3/18 disagreement) for one transcript and 82% (reflecting 46/56 agreement and 10/56 disagreement) for the other (see Appendix 7, p.236, for example). Campbell et al. (2013, p.310) point to research that has suggested that "an 'inter-coder correlation' of 79 percent ensures a 'relatively high degree of reliability'" and that, "an intercoder reliability range of 70 percent to 94 percent was 'acceptable' to 'exceptional'". The authors also noted that lesser figures may be considered acceptable for exploratory research. As such, it is considered there was adequate and good agreement in the current study. Additionally, the disagreements were resolved by discussion. The negotiated agreement method has been discussed by the literature and some studies have suggested that this process can increase the percentage of agreement by up to 40%, although it is also recognised that this process can also be affected by the interpersonal dynamics between the coders (Campbell et al., 2013).

Table 3.2: Description of Themes and Sub-themes

Dental Anxiety in Individuals with ASD	**Anxiety in Individual with ASD**	**Sensory Sensitivities**	**Coping Strategies**	**Other**
Fear of the Unknown Individuals who like to know what is going to happen at the dentist and are worried about unpredictability	*Fear of the Unknown* Individuals who like to know what is going to happen, and are worried about unpredictability	*Sight* used to describe individuals who are sensitive and cannot cope with stimuli to do with their sight, such as light	*Support to Cope (Family/ Therapist/ School/ Dentist)* Individuals and families who had support from different sources, whether it was school, their own family, therapist, dentist etc. to overcome their anxiety	*Comorbid Conditions* Any medical health condition, mental condition, or learning disabilities that the child or individual with ASD is diagnosed with
Family History of Dental Fear and Anxiety Individuals who had parents and/or siblings who fear the dentist	*Type of Anxieties* Individuals with other type of anxieties (e.g.; social anxiety, food anxiety). In addition, to individuals who are described as very anxious in general	*Smell* used to describe individuals who are sensitive and cannot cope with stimuli to do with their sense of smell, such as strong odours	*Preparations for the Dentist Appointment/Treatment* Methods that are used by parents, dentists, school or individuals themselves to get ready for the dentist (e.g. talking to the child, social stories, web searches etc.)	*Effects of Medications* Individuals and children who are taking regular medication, which affect their teeth
Physical Symptoms of Dental Fear Individuals who exhibit physical symptoms knowing they have a	*Family History of Anxiety* Individuals who had parents and/or	*Taste* used to describe individuals who are sensitive and cannot cope with stimuli to do	*Taking Care to Prevent Problems* Strategies taught to individuals to do as precautions, such as brushing their teeth thoroughly	*Behavioural Problems* Individuals who exhibit negative behaviours or act poorly when anxious (e.g. throwing tantrums)

dentist appointment or when they are at the dentist, such as sweating, churning in their tummy, etc.	siblings with anxiety problems	with their taste, such as toothpaste		
Avoidance of Dentist/Dental Visits Individuals who refuse to engage, avoid going, or try to escape going to the dentist or receive dental care/treatment	*Physical Symptoms of Fear* Individuals who exhibit physical symptom when anxious such as, sweating	*Hearing* used to describe individuals who are sensitive and cannot cope with stimuli to do with their sense of hearing, such as loud music	*Modelling and Family Visits* Individuals with families who do not exhibit anxious behaviours (for example, who model courage) and who also visit the dentist as a family and watch their family members at the dentist	
Feelings about the Dentist/Dental Visits The parent of a child with ASD or the individual himself/herself and a description of their feelings towards the dentist and the dental visits	*Avoidance* Individuals who refuse to engage, avoid going, or escape anything that they are anxious about	*Touch* used to describe individuals who are sensitive and cannot cope with stimuli that touch them or other people touching them	*Good Experience with the Dentist* Individuals who had a dentist who provided them with a pleasant and good experience by providing good treatment and a good way of dealing with the child and the family	

Social Impact of Dental Anxiety Individuals who are afraid or scared of what people and/or dentist would think of their teeth or how they take care of them	*Previous Negative Experience* Individuals who have gone through an experience, or saw someone go through a bad experience, which affected them negatively because it was traumatic or had bad impact on them (death, adoption, etc.)	*Vestibular* Awareness of body balance and movement. The sensations of body rotation and of gravitation and movement	*Reinforcement and Rewards* Individuals who had treatment followed by treats or gifts (e.g. a visit to the park or a sticker, etc.)	
Negative Thoughts about the Dentist Individuals who anticipate bad things will happen to them at the dentist and by the dental surgeon		*Proprioception* ability to sense the position and location and orientation and movement of the body and its parts	*Well Prepared Dentist with Good Practice* Dentists who had good knowledge of, or experience working with children with ASD, even if they are not a special needs dentist. He/she provides good practice and meet the patient's needs	
Previous Negative Experience Individuals who have been through an experience in the dentist, or have seen				

someone go through a bad experience in the dentist, which affected them negatively because it was traumatic or had bad impact on them				
Pain Individuals who worry about the pain of dental treatment and getting hurt at the dentist.				
Routine - Individuals who prefer to do the things the same way (e.g. use the same toothbrush, visit the same doctor) - Doing things more often to make it feel more familiar				

3.5 Results

The present study used thematic analysis to understand and illustrate the qualitative findings. The present results section presents the findings according to the order of the main themes identified, with the sub-themes discussed under each of the main themes.

THEME 1: Dental Anxiety in Individuals with ASD

The first main theme to arise was an overall confirmation of the reality of dental anxiety in individuals with ASD. Ten sub- themes emerged within the main theme of dental anxiety in individuals with ASD, namely: fear of the unknown; pain; avoidance of dentist/ dental visits; negative thoughts about the dentist; previous negative experience; family history of dental fear and anxiety; feelings about the dentist/dental visits; physical symptoms of dental fear; effect of poor care of the teeth on dental anxiety; and routine.

Fear of the Unknown

This was a theme evidenced in the participants' accounts in relation to going to the dentist, in particular, the worry of not knowing what the visit would involve and the possible things the dentist might do. This issue was highlighted in nine interviews; for example, the mother of an 11-year-old boy diagnosed with Asperger's syndrome described her child's worries:

> *It is probably a combination of all those things really. It is the fear of the unknown I would say.* (Participant 9)

A 26-year-old female diagnosed with ASD stated how she found going to the dentist very worrying because it was unpredictable:

> *You just don't know what's going to happen at the dentist's surgery. It's all unpredictable and scary.* (Participant 3)

The mother of a boy diagnosed with Asperger's syndrome explained her child's worries:

> *It's the whole not knowing what's going to happen to him. I think that unsettles him and makes him 'go into one'*. (Participant 6)

Pain

Five of the interviewees related degrees of perceived pain that they associated with attending the dentist and the machinery being used by the dentist.

A parent described her child's worries:

> *He is probably worried that he is going to hurt him, cause him pain.* (Participant 5)

An adult with autism stated his concerns of pain:

> *The only ones I am fearful of – that a lot of so called 'normal' people are as well – is if I am unfortunate that the dentist is saying they need to use a drill, seeing I have got something wrong with my teeth, or an injection. I'm really fearful of those. But that was more because I know I might be experiencing pain*. (Participant 2)

Another adult diagnosed with ASD described her fear:

> *I am worried that it is going to hurt, that I am going to get pieces of tooth from getting a filling down the back my throat.* (Participant 4)

She added to this by describing what annoyed her the most about the dentist:

> *I think it is mostly probably like waiting for it to hurt. I spend the whole time waiting for it to hurt.* (Participant 4)

A parent of a 13 year old girl diagnosed with ASD described her child's worries as follows:

> *She is afraid they are going to hurt her. She is afraid they are going to hurt her for no reason. So that is her fear, it is fear of being hurt*. (Participant 10)

A 26 years old girl with ASD described what worried her:

> *The pain bit, the pain of the injection and the drill*. (Participant 3)

Avoidance of Dentist/Dental Visit

Eight of individuals with ASD tried to avoid, refuse, or escape dental care or treatment, which is shown in some of the examples here.

A parent of child with ASD describe her son's behaviours to avoid the dentist:

> *Before we actually get into the dentist he'll start saying he doesn't want to go and will start trying to pull back and stop us from going in*. (Participant 6)

Another parent described her child's behaviour:

> *We take her to the dentist. She didn't want to engage at all*. (Participant 8)

An individual with ASD stated:

> *I have not gone to the dentist since I had a choice.* (Participant 1)

Another mother added*:*

> *No, she just refused to go to the dentist*. (Participant 10)

Negative Thoughts about the Dentist

The interviews demonstrated that five participants discussed negative thoughts about the dentist or dental visits, such as the worst that might happen and that the dentist would hurt them.

A young woman with ASD talked about the thoughts that crossed her mind when she visited the dentist:

> *The worst scenario is going through my mind. The worst can happen at the dentist.* (Participant 3)

The mother of a 13 year old with ASD added that her child worried about not knowing what the dentist was going to do to her:

> *She thinks they are going to do more to her than what I am saying, that maybe we are not telling her the truth. That a check-up would involve this, this and this. That actually, when you are there, they might really do a lot more.* (Participant 10)

Another mother added that her son worried about having something done to his teeth:

> *I think he is worried that he is going to do something to his teeth.* (Participant 5)

Previous Negative Experience

Six participants who talked about negative experiences they had been through when visiting a dentist, which could have resulted in a bad impact on them. Some experiences were found to be traumatic to some individuals.

A 23-year-old with ASD recalled how the people around him would often remind him about a past incident at the dentist:

> *When I was really young, my mum was trying to show to both of us that there is nothing bad going to happen at the dentist. And basically the dentist went through her artery, I think. There was a mass of blood apparently and my mum spent the entire time trying to smile at us two whilst the dentist was shoving tons of paper towels in her mouth because there was blood pouring out of her mouth.* (Participant 1)

The parent of girl diagnosed with ASD described her child's negative experience:

> *When her adult teeth started her baby ones had not dropped out, so she had two sets of teeth, which I had never seen before. I flew to the dentist and said 'oh my goodness look at this'. She had a look and pulled one of them out, pulled the baby tooth out, which frightened the life out of my child. There was no explanation that this is what she was going to do and that put us back years and years.* (Participant 8).

Another adult with ASD added:

> *Last time I went to the dentist I had some fillings. It was generally unpleasant. I quite often don't react to the anaesthesia very well, it just doesn't affect me, and so it can be quite painful. There is a whole process of them injecting me and me saying it still hurts and then they're having to do it again.* (Participant 4)

Family History of Dental Fear and Anxiety

Nine of the interviews highlighted an association between parental dental anxiety and anxiety in individuals with ASD. However, parents may be aware of the impact of their worries on their children and take conscious steps to guide their child towards accepting the treatment, as one parent of a child with ASD described:

> *I am quite nervous of the dentist. But then, when I had the children, I was like you cannot. You have got to be brave and show them that it is actually a good thing to do, to go to the dentist.* (Participant 9).

A mother of a child with ASD talked about her anxieties:

> *I do get anxious about going to the dentist. But again, because I know it worries my child so much, I really have to hold back and I have to pretend to myself it is absolutely fine and I just try and put it out of my mind.* (Participant 5)

An adult with ASD described her mother's feelings toward the dentist:

> *I don't think that my mum particularly likes the dentist*. (Participant 4)

Feelings about the Dentist/Dental Visits

Individuals with ASD expressed different feelings; the interviewer asked how they felt about going to the dentist, which is discussed below.

A mother described her daughter's feelings toward the dentist:

> *Her verbal skills weren't good enough I think. What she used to do was just shutdown. She would go very quiet, it was very difficult to engage with her. It was hard to know whether she didn't understand. I think now it was just it is just too scary, I can't even think about that, go away.* (Participant 8)

A young adult with ASD talked about how he felt about the whole dentist experience:

> *I dislike it immensely. I just don't like the entire process.* (Participant 4)

A man with ASD described how he felt about going to the dentist:

> *I find going to the dentist is a torture*. (Participant 2)

Physical Symptoms of Dental Fear

Four of the participants talked about the physical symptoms they or their child experienced when going to the dentist. Some said their child was anxious but that they could not identify any physical symptoms.

A 26 year old woman with ASD described how she felt before going to the dentist:

> *I always get this awful knot in my stomach before I go to every dentist appointment.* (Participant 3)

A mother expressed her child's fear of pain*:*

> *And physically, all the colour will drain out of his face so he will be really white.* (Participant 5)

A mother of a girl with ASD described the looks of her anxious child:

> *She would sweat through her hair and become very glowing and red.* (Participant 10)

Effect of Poor Care of Teeth

Two of the individuals discussed their worries about having bad teeth and how it would affect them socially.

An individual with ASD described her worries about having bad teeth:

> *I guess I just think about how gross it would be to have really manky teeth so I do it that way.* (Participant 4)

She added:

> *I get scared that the dentist is going to sort of think that I don't brush my teeth because my teeth are bad*. (Participant 4)

An individual with ASD described her own worries of having bad teeth:

> *Yeah, it's also an image thing it's part of your thing, one of the first things a person will see and if they don't look nice, if you have a falling out teeth or teeth with gross stuff on them. It just makes you not want to look at anybody or smile at anybody*. (Participant 3)

Routine

Individuals with ASD prefer routine and things they are used to. Dental visits usually happen once every six months, which means that such visits are generally perceived as outside of the

usual routine and are therefore harder for the person to get used to and become familiar with. Nine of the participants discussed the issue of routine in relation to dental anxiety.

A 23 year old individual with Asperger's syndrome described his worry:

> *I don't know. I mean, part of the matter is it is a break in routine.* (Participant 1)

One mother described the infrequency of the dental visits as opposed to other things that occurred more regularly:

> *I think because you do not do it very often, that has built up a lot of anxiety over*. (Participant 9)

Another mother also expressed her worries regarding the frequency of dental visits and how that affected her child's anxiety:

> *What he needs is structure and routine. And if there is a change to that, I suppose with the dentist because it is only once every six months, all of a sudden there is a change in the routine. And he has to go somewhere and ok he has been there for years, but the last time… It is like a new time every time, because six months is a long time for him. He forgets the fact that there was no problem.* (Participant 5)

THEME 2: Anxieties in Individuals with ASD

Most of the interviews showed that individuals with ASD were anxious in general. Six sub-themes within the category of anxieties therefore emerged from the analysis. These were: anxiety about other things; fear of the unknown; family history of anxiety; physical symptoms of fear; avoidance; and previous negative experience.

Other Types of Anxiety:

Individuals with ASD have high rates of anxiety, which was demonstrated in the interviews, as seven interviewees reported having some kind of anxiety.

A mother of a child with Asperger's syndrome talked about her child:

> *He was always very anxious. Even as a baby he seemed quite scared of a lot of things. When he was a toddler he was anxious about a lot.* (Participant 6)

An individual with ASD expressed her anxieties:

> *I am afraid of heights*.

She added:

> *One big phobia that triggers panic attacks is being in a situation that I am not familiar with.* (Participant 3)

Another parent of a child with ASD said:

> *Generally, he gets extremely anxious about anything that he has to go to.* (Participant 5)

A 26 year old woman with ASD described her anxieties:

> *I guess a moderate amount of social anxiety. I guess mild food anxiety sometimes.* (Participant 4)

Fear of the Unknown

Fear of the unknown and unpredictable situations were the most common experiences and were raised a number of times by eight of the participants.

A young woman with ASD described what triggered her panic attacks:

> *Being in a situation that I am not familiar with and that is unpredictable… Definitely invited into strangers' houses. Yeah unpredictable and scary things really.* (Participant 3)

A mother described her child's anxiety:

> *He gets extremely anxious about anything that he has to go to, anything that he is unfamiliar with.* (Participant 5*)*

She added:

> *Even if it is a nice thing he gets anxious, even if he is going on a school trip he will get anxious about it because is the unknown*. (Participant 5)

Family History of Anxiety

Two interviewees showed that anxious individuals are inclined to have family members who are anxious as well.

A 26 year old woman with ASD described her sister's anxiety**:**

> *Maybe my sister is afraid but she never talks to me I don't know. My sister gets afraid of a lot of thing.* (Participant 3)

A mother talked about her own anxiety:

> *One thing that does make me feel anxious actually, which does affect me, is flying. And that has got worse through the years*. (Participant 5)

Physical Symptoms of Fear

There are behaviours that are exhibited when an individual is anxious or afraid. Two participants discussed what they experienced or what their child experience when they were anxious.

An individual with ASD described his feeling when he is anxious:

> *I mainly freeze when I get overloaded and stuff so it is kind of so neurotypical generally.* (Participant 1)

A parent described her son's fears and anxieties:

> *He used to get so anxious that he used to make himself sick at school.* (Participant 5)

Avoidance

A man with ASD described how he avoided situations that made him anxious or caused him discomfort because of his sensory sensitivity:

> *I hate having my hair cut… the foster mum had i.t On one occasion she told me in the car when we were heading home she said: "oh I'm going to cut your hair." I got of the car and fled*. (Participant 2)

Previous Negative Experience

Individuals with ASD experience persistent and pervasive anxiety in a wide range of their daily experiences, especially those who had been a negative experience. One individual with ASD described how a negative experience in her life had affected her:

> *I did start job hunting but I kept getting lots of rejections until I eventually gave up and I was going through a difficult time as well because my brother had died and my mum was sad around the house and so therefore we were all sad and snappy. I just had trouble functioning everyday things there were days when I just didn't want to help out with chores and my social difficulties seem to be getting worse*. (Participant 3)

THEME 3: Sensory Sensitivities in Children with Autism

A very common and important theme evident within the participants' descriptions was around sensory sensitivities and how these impacted on the individuals' experiences of fear and anxiety about going to the dentist; because of its importance and how frequently it was mentioned the researcher decided that it should be a theme on its own. The dentist's use of the light, machinery such as drills and the movements of the dentist chair were distressing, which

caused degrees of distress and discomfort in many accounts. This was eventually broken down into seven sub-themes, namely: sight; smell; taste; hearing; touch; and vestibular and proprioception.

Sight

Four of the participants identified the bright lights as being particularly problematic. Given the unusual brightness of the lights used in dentistry, this can pose a problem for both the patient and the dentist attempting to perform the work, indeed as was seen:

A 23-year-old adult with ASD described his discomfort with the light used in the dental clinics:

> *The most memorable thing always is the light. You have to stare into that light thing and it is horrible. It burns your eyes.* (Participant 1)

A mother of an 11 year old boy with Asperger's stated:

> *I say the sounds that are going on and probably the lighting as well, because the lighting is really, really bright in there. That probably affects him too.* (Participant 9)

A mother of a 9-year-old boy with Asperger's syndrome described her child's sensitivity towards the light:

> *You go in there, you know, when they bring the light down over their face. The dentist doesn't use that because he can't cope with the light at all*. (Participant 7)

Smell

Three of the participants spoke about the smells that are in the dental clinic, and these were difficult for individuals with ASD to cope with.

A mother talked about the environment of the dentist and how it affected her child:

> *Obviously there are the smells and the environment everything that goes into it as well, because he's very affected by his senses.* (Participant 6)

Another added about her son being sensitive to the smells that are at the dentist's:

> *But if a child's very sensitive, again with my son is, the smell, you walk into that dental room, the mouth wash has got a funny smell and you know what they make you rinse your mouth out with.* (Participant 7*)*

Taste

One participant talked about her child's sensitivity to taste. Therefore, it can be said that with this particular sample, it is not one of things that were commonly mentioned as particularly troubling. The mother of a girl with ASD talked about her daughter's sensitivity:

> *She is highly sensitive to taste as well, obviously.* (Participant 10)

Hearing

Four participants spoke about the loud noises that are in the dental clinic, such as the ones coming from the use of machinery, which were difficult for individuals with ASD to cope with. A mother of a 13 year old girls with ASD discussed the possible reasons for her child's anxiety:

> *I still don't know because it is in your mouth it is also loud and close up. (*Participant 8)

Another mother added about her child's sensitivities:

> *He didn't like dizzy loud places.* (Participant 6)

Touch

Five of the participants suggested that many individuals with ASD do not like the experience of being touched by the dentist and that this made them feel uncomfortable and resistant to receiving dental care. An adult with ASD, diagnosed with Asperger's syndrome, described his feeling about being touched at the dentist:

> *I dread going to the dentist because I know I am going to have fingers and other things prodding me in my mouth. I do not like to be touched, especially not in in my mouth.* (Participant 2)

A mother of a boy diagnosed with Asperger's syndrome describes her son's sensory sensitivities regarding dental care:

> *Maybe it is sensory. I don't know. Maybe he doesn't like the dentist putting his hand in his mouth*. (Participant 5)

A mother of a 13 year old child described the unpleasant experience of having an x-ray at the dentist:

> *It is a pretty unpleasant experience, having those bits of cardboard in your mouth and with your mouth in a particular position*. (Participant 8)

Vestibular and Proprioception

In the dental context, these issues arise with the experience of having to sit on a large moving chair and be guided backwards into an unusual position. This experience may be more unsettling due to the movement of the chair and the large items that surround the chair, including the lights and machinery. Five interviewees discuss the effect of the dental chair on dental anxiety.

A mother raised her 13 year old's sensory concerns about the chair. She said:

> *I think the whole lying on chair thing and lying back was something that she couldn't cope with…. I think the fact that the chair moves also scares her. Probably, I am guessing here, just the chair, the machinery and the drills all hanging around and everything I am sure that is probably terrifying for her knowing how she is about moving machinery*. (Participant 8)

Another mother added:

> *You think even as an adult, you sit in that chair, it's quite scary when they start pushing it back and you're going back thinking, oh my God, and that's the bit he used to hate.* (Participant 7)

THEME 4: Coping Strategies

The ways in which individuals cope with anxiety differ from one person to another. Thus, interviewees talked about different strategies that helped them cope with their dental anxiety, such as having a clear and well-informed understanding of what to expect at the dentist. This theme expanded in the second analysis into seven sub- themes, namely: support to cope (family/therapist/school/dentist); preparations for the dentist appointment; taking care to prevent problems; modelling and family visits; good experience with the dentist; reinforcement and rewards; and well prepared dentists with good practice.

Support to Cope (Family/ Therapist/ School/ Dentist)

Having support, whether from family or a therapist, can affect the way a person copes with anxiety. Five parents reported various measures to inform and familiarise their child with the process, including buying children's books on the subject.

A girl with ASD had a good support system, according to her mother's description:

> *I don't think we have been anything but positive, bought her books on it, children's books on it. People have talked to her about it, her family have talked to her about it*. (Participant 10)

A mother of a child with ASD described how she and the dentist helped her son to cope with the dentist's appointment:

> *When we go in, as long as they give him the time and he's allowed to go in. We go in, he sits in my lap, she explains everything to him and what's going to happen. He then helps adjust the chair, helps her get all the stuff ready, helps her put her mask on*. (Participant 7)

Another parent added:

> *I would sit in the dentist's chair and she could sit on my lap*. (Participant 8)

Preparations for the Dentist Appointment

Three participants spoke about the time taken at the beginning of the treatment to explain what was going to happen. Several parents suggested that familiarisation was key and that attending the visits regularly made it easier for her child to cope.

A mother described how frequent visits to the dentist helped her daughter to get prepared:

> *I took my two girls every other month to try and get them used to it, she would just about open her mouth. By going regularly we got to the stage where the dentist could look*. (Participant 8)

A mother of a boy with ASD and haemophilia describes how she explained to her worried son about dental procedure, to get him prepared:

> *But he knows that, we have tried to explain to him that if he needs anything done because of his haemophilia it would probably have to be done in the hospital anyway so it wouldn't be done there.* (Participant 5)

Taking Care to Prevent Problems

Three participants discussed the regime they followed to maintain good oral health and prevent dental problems.

A mother described how her son took good care of his teeth despite the medication he was taking:

> *So while he cleans his teeth twice a day, this is why the dentist wanted to try and start putting the fish oil on his teeth because she is concerned about how much sugar there is in all his medication.* (Participant 7)

Modelling and Family Visits

Five participants talked about bonds with family and how important this was during the visit, stating that they used to go to the dentist as a family. As family would all receive their treatment at the same time, the child with ASD was able to see their family go through the experience before they did.

A young man with ASD described how he used to watch his mum at the dentist:

> *My experience in the dentist has always been with watching mum or just prodding my teeth*. (Participant 1)

A mother of a child with ASD talked about modelling:

> *The first time we went I remember he refused to get on the seat. I think my husband went first and then our youngest son, at this point he would have been about one and a half, two years old, and he went on and did everything okay and we hoped that my son with autism seeing his younger brother it, it would then feel okay to do it but he still wouldn't get on the seat.* (Participant 6)

Another mother mentioned how they all visited the dentist as a family, and her son got the opportunity to see them all in the dentist's chair:

> *Yes, we go as whole family. We always do that, we have always gone as a family so we all sit in the chair so he can see what we all go through.* (Participant 5*)*

Good Experience with the Dentist

Three participants talked about having a cooperative dentist who helped them and gave them a good experience.

A mother described her experience with the dentist:

> *Mike and I made our plan up but that is because he is lovely and he was already my dentist.* (Participant 8)

A parent of a child with ASD described her experience with a good dentist:

> *The dentist he sees, she's really good. She has no lights on. He's allowed to do the chair*. (Participant 7)

Reinforcement and Rewards

Six participants talked about the way positive rewards could serve as a counterbalance to negative feelings about the visit, saying their child liked being given tubes of toothpaste by the dentist, or enjoyed other rewards, such as chocolate.

A parent talked about her child's love for toothpaste tubes the dentist gave him:

> *He likes to have a tube of toothpaste... So she always makes sure she's gone out and bought the ... she always gives him a tube of toothpaste because he uses Sensodyne toothpaste, so she always gives him a special tube of his own toothpaste. And that's kind of ... he looks forward to having his own, because then he's got his own stuff, because then he can put it in his own little box in the bathroom at home.* (Participant 7)

Another mother talked about her son's love for chocolate and takeaway food, so this is what she used as a reward for going to the dentist:

> *Either a takeaway or chocolate, he loves chocolate but I must admit I reward myself with a chocolate after I have been to the dentist.* (Participant 5)

A young man with ASD described how that he reinforced his resolve to go to the dentist by having chocolates:

> *Eat chocolate*. (Participant 1)

A mother discussed how reinforcement with her son came from the dentist themselves:

> *The dentist themselves do reward him now. They always give lots of praise and give stickers and sometimes they have little sachets of tooth paste and things like that and they'll let them choose something from there. And obviously we praise him for it as well. (*Participant 6)

Well-Prepared Dentists with Good Practice

There is a suggestion that there is a significant role to be played by the dentists themselves when treating patients with ASD. Six interviewees stated that having a well-prepared dentist was a great help. Therefore, an awareness of the particular sensitivities and problems help dentists meet their specific patient needs and professional techniques may be improved by training.

An adult with ASD talked about having an understanding dentist, which helped him deal with his anxieties and therefore receive dental care:

> *Thankfully the dentist I am with at the moment is a special needs dentist who deals with people with autism and learning difficulties. The reaction I get is 'Ok, we understand you don't like being touched. That is okay, but you should come and visit a dentist more often*.' (Participant 2)

The mother of a child with ASD said about her child's dentist:

> *The dentist is very good and knows he has got autism and is very calm and very nice to him and tells him exactly what he is doing each time*. (Participant 5)

THEME 5: Other

Further sub-themes were identified and grouped together under the main theme of 'other'. These included the effects of medications and behavioural problems.

Effects of Medications

One participant talked about the medications her child was taking and how they affected the wellbeing of his teeth:

> *It does because it's so sweet… and they're like very sweet drinks and yoghurts.* (Participant 7)

Behavioural Problems

Three participants, and especially parents of children with ASD talked about the behaviours their child exhibited, which were problematic and could hinder the parent and the child from proceeding with their plan/activity. They also described the negative impact on people around them.

A parent of a child with autism described her son's behaviour:

> *Even going to the shops he will have a melt-down trying to get into lifts and things like that, and recently any sort of activities that have happened at school say, for example, sports day, or if they put plays on and things like that he refuses to take part, and he can become quite upset and tearful about it all*. (Participant 6)

A mother of an 11 year old boy with ASD described his behaviours:

> *He will not be able to cope with it and how it manifests itself in the home is with his behaviour. He can be extremely horrible to his younger brother*. (Participant 5)

3.6 Discussion

The qualitative interviews provided a rare opportunity to gather data directly from the perspectives of people with ASD and explore the issue of dental anxiety in individuals with ASD. The interviews were able to gather information from both the individuals affected and the parents of children with ASD, providing two different and complementary perspectives on the topic. The interviews asked open-ended questions and also permitted participants to add anything from their own knowledge if they wanted. This data enabled the study to identify factors that case dental anxiety for those affected by this problem in practice and probe the

minds of the parties most affected by this problem, without any preconceptions to limit the responses. These factors were then explored further in the third study, along with the factors identified from the perspective of professional dentists to identify predictors of dental anxiety.

The results of this study indicate that dental anxiety in individuals with ASD is a hindering factor in the receipt of dental treatment and that this can be understood in the context of the five main themes identified by this study, namely: dental anxiety in individuals with ASD; anxieties in individuals with ASD; sensory sensitivities; coping strategies; and those aspects grouped under the catch-all category of 'other'. The following discussion will cover the major topics that emerged from the study and highlight the factors that are explored in detail in Study 3.

THEME 1: Dental Anxiety in Individuals with ASD

In terms of dental anxiety, most of the participants stated that their anxiety was affected by the lack of predictability and knowledge about what was going to happen at the dentist's. This concern cut across both the general anxieties and specific dental anxieties theme.

Fear of the Unknown

Fear of the unknown has been explained in the literature as the intolerance of uncertainty. This model suggests that uncertainty is stressful and upsetting and events that have not been predicted therefore feel negative and threatening and lead the anxious individual to avoid them (Wigham, Rodgers, South, McConachie, & Freeston, 2015). This is linked to the concept of the insistence on sameness and both these models share common characteristics (Boulter, Freeston, South & Rodgers, 2014). For example, Participant 12 said the issue had been 'not knowing what's going to happen' at the dentist's surgery. Further, as recognised in numerous studies (Gomot & Wicker, 2012), individuals with ASD generally exhibit unusual processing of unpredictable events (Cocia et al., 2012; Field, 2006), which could also serve to make unfamiliar procedures feel traumatic and uncomfortable.

In terms of ASD characteristics, fear of the unknown could possibly be linked to a reduced capability to consider the perspective of someone else (in this case, the dentist), or

understand their perspectives (imagine what the dentist is about to do), due to relative deficiencies with their ToM (Goldstein & Winner, 2012; O'Nions et al., 2014). That is, a child with ASD may struggle to imagine what the visit will involve, due to their relative inability to read and interpret the external world and reasonably guess what it could mean. In the present sample, it was evident that some children with ASD and young adults were anxious about the dentist's because they could not predict what would happen at the dentist. Questions are therefore raised regarding whether or not children with ASD adequately understand the rationale for the treatment, or whether they are seeing the visit as some kind of dangerous cause for alarm.

The ability to imagine future possible experiences has also been discussed in terms of episodic future thinking (Lind, Williams, Bowler & Peel, 2014) and individuals with ASD have been found to have a reduced capacity to mentally construct possible future occurrences. This suggests that a fear of 'the unknown' is inherent in those with ASD, simply due to their innate deficiencies in imagination.

Family History

Both Participant 2 and 9 were parents who considered the impact of their anxiety on their child's experiences. Both these parents seemed to consider that displays of anxiety in front of their children were unacceptable and had to be overcome. The impact of parental dental anxiety upon their child's dental anxiety has been well-studied (Themessl-Huber, Freeman, Humphris, MacGillivray & Trezi, 2010) and as such, the present findings are consistent with existing literature. Research has found that the impact of parental anxiety may be due to hereditary genetic factors, but also due to learning, parenting styles and parental personality traits (Krikken, Ten Cate & Veerkamp, 2010).

The present research highlights the importance of parental behaviour, as parents were aware that their fears were manifesting in front of their children through their behaviours and attitudes. However, it is recognised that the present study did not examine genetic variables and so the exact nature of the parental influence is not clear from the present research. It may also

be difficult to measure the impact of parental anxiety because parents may be inclined to give more positive analyses of their behaviours in interviews (Creswell & Miller, 2000), or may not have fully recognised how their children were interpreting or responding to their anxieties.

Previous Negative Experience

Another important finding was the impact of previous negative experiences that the subjects had been through, which influenced the development of their dental anxiety and this finding matched those observed in earlier studies (Mendoza-Mendoza, Perea, Yañez-Vico & Iglesias-Linares, 2015; ten Berge, 2008). In the present study, participants mentioned particularly distressing experiences, such as seeing a lot of blood and also a tooth being pulled out. These experiences can be expected to be distressing for TD children, let alone those with ASD. These negative conclusions were not specifically due to the ASD but rather, just accidents they happened to witness during their dental visits. While incidents such as these may not be uncommon, they can be particularly distressing for individuals with ASD due to their relative inability to process their experiences (Chalfant, 2011) and their predisposition to experience greater anxiety in general (Cocia et al., 2012; Farrugia & Hudson, 2006).

The relevance of previous distressing experiences with regard to the ASD population has to be weighed with their ability to remember previous dental visits. As this study has shown, some parents said their child forgot their previous visit altogether and that their poor memory of the previous visit was the cause of them feeling anxious about the current visit. It is therefore interesting that children with ASD have been found to both forget what going to the dentist involves, but also that they are likely to be put off by previous negative experiences. This raises questions about the ways distressing and traumatic memories are stored by individuals with ASD.

There may be few ways that dentists and parents can overcome previous negative impressions and this suggests that adequate information about the procedures in the current visit will be more important. Parents may need to consider switching dentists if necessary, or going to a dentist in a clinic that is especially designed for individuals with special needs.

Pain

Children with ASD have also been found to have an intolerance to physical pain (Courtemanche & Black, 2016) and also to demonstrate aversive reactions to stimuli they consider to be unpleasant, including dental procedures (Daughters, Palermo, & Koh, 2007; Tordjman et al., 2009). The results of the current study demonstrate that the main issue in terms of pain for the participants was the fear of pain. Pain is something recognisable and therefore is a separate anxiety to a fear of the unknown. It is normal for the TD population to be averse to pain although it becomes problematic when the anxiety is exaggerated and therefore becomes a barrier to treatment. Given that fear of the unknown was so significant, it is interesting to question what this fear was, in fact, based upon and to distinguish between whether the fear was due to a general fear, or anxiety about 'the unknown', or to a fear of pain (Ramos-Jorge et al., 2013); this may also reflect upon what a patient with ASD is able to imagine.

In terms of ToM, it is recognised that a fear of pain may not require a ToM because the pain is felt personally by the individual. In terms of fear of the unknown however, a ToM may help an individual assess whether the dentist wishes to cause them pain or not (Sinhaa et al., 2014). A search of the literature revealed there have been no studies conducted on the correlations between dental anxiety and ToM and this is an interesting area because it probes the subject of the individual with ASD's personal perception of the dental visit, which is difficult to understand for those who do not have ASD. Comparing the ASD and TD populations can help identify the essence of ASD perception and what it is that individuals with ASD experience when they consider visiting the dentist. Indeed, this has been one of the main aims underlying the present thesis.

Routine

As discussed in the literature review, EF may be a factor that is relevant to the individual with ASD inability to cope with the change in routine that is necessary to make the visit. As stated, this may be due to the natural tendencies to repeat behaviours, which therefore makes such individuals resistant to change (Vanegas & Davidson, 2015). Experiences like this are

common in the literature and the disruption to routine has regularly been identified as contributing to resistant attitudes to dental care (Limeres-Posse, Castaño-Novoa,, Abeleira-Pazos, & Ramos-Barbosa, 2014).

There have been no recent studies conducted on the relationship between EF and dental anxiety, although the findings from the present study have suggested there is a relationship between dental anxiety and breaks from ordinary routine. Clearly, the ability to remember a past event will be related to the extent to which an individual with ASD considers it to be a break from the ordinary routine and the less frequently the event occurs the more likely the individual with ASD will consider the event to be out of the ordinary routine. However, the precise interplay between memory and EF here is unclear and further research in this field would be useful to better understand why the individual with ASD suffers in this way and what can best be done to overcome these problems.

As one mother suggested, children with ASD can often feel like each visit is taking place for the first time, even if they have been to the dentist a number of times before, due to the length of time between each visit. As such, these findings may implicate the individual with ASD's working memory, which has typically been considered an aspect of executive function (Ozonoff & Strayer, 2001), although long-term memory will also be at play.

Long term memory, as it is related to ASD, has not received much discussion in the literature as compared with working memory. This may be due to the fact that such studies will need to be longitudinal in nature and therefore require a greater amount of planning. Research by Boucher, Mayes and Bigham (2012), for example, found that both High Functioning Autism (HFA) and Low Functioning Autism (LFA) entail reduced ability to remember emotion or person-related stimuli, while recognition and free recall of meaningful or structured stimuli is generally worse for LFA than HFA, although that study was not conducted over a long period. It is, however, interesting to question whether a visit to the dentist would best be characterised as an emotion-based stimulus (for example, due to memories of pain or trauma), or a person-related memory (for example, where the memory is of the dental surgeon).

In terms of long term memory, the present study revealed that some children with ASD can feel as though each dental visit is taking place for the first time, the child having apparently forgotten the previous visit completely.

THEME 2: Anxieties in Individuals with ASD

Several informants talked about their general anxieties and this is consistent with literature that has found individuals with ASD to be more likely to suffer from comorbid anxiety disorders than their TD peers (de Bruin et al., 2007; Klin et al., 2005; MacNeil et al., 2009; White et al., 2009). This suggests anxiety is a symptom that needs to be addressed for individuals with ASD in general, even outside of the dental context. As the literature review revealed, anxiety is often affected by the IQ level of the individual with ASD (Charman et al., 2011), although this variable was not measured in the present research.

The literature review also covered the impact of parental anxiety on their child's level of anxiety (Goettems et al., 2011). In the present research, Participant 12 talked about her sister's anxiety and this could suggest either or both genetic and environmental causes for anxiety within families.

THEME 3: Sensory Sensitivity

The present study confirmed that sensory stimuli in individuals with ASD affect dental anxiety, which is consistent with existing research (DeMattei et al., 2007; Shapiro et al., 2009; Tomchek & Dunn, 2007). The study identified that all the senses were affected by dental visits, including sight, sound, taste and touch, and the emphatic responses from the participants regarding this issue suggest they considered sensory sensitivity to be a particular problem. For example, Participant 1 said, "You have to stare into that light thing and it is horrible" and Participant 2 said, "The lighting is really, really bright in there". The present study suggests there is a particular problem caused by sensory sensitivity in the dental context and, as discussed, there remains a lack of literature conducted in this particular field.

Sensory sensitivity has been identified as a factor that affects individuals with ASD in particular (Shapiro et al., 2009). This is most likely due to the overwhelming sensory stimuli

present in the dentist's surgery, such as the machinery used for cleaning the teeth, the bright fluorescent light, continual touching in or around the mouth by the dentist, and the taste and smell of the different oral care products (Stein et al., 2011). The study found that sensory sensitivity was an issue often raised by individuals affected by ASD and this was therefore considered an important issue to examine in the third study. In this respect, it is clear that many features of dental treatment are incompatible with the nature of the ASD disability and few can be avoided. This makes the finding of adequate solutions to reduce dental anxiety even more essential.

THEME 4: Coping Strategies

Given the above discussion concerning fear of the unknown, it may be logical to conclude that repeated visits to the dentist may be of assistance in reducing the 'unknown' aspects. As such, the theme of routine can be related to the coping strategies theme. The present findings suggest that familiarity with dental visits and the interval between them can be particularly problematic for individuals with ASD. While making such visits more frequent may be impractical, methods to establish the routine aspects of the visits, such as associating them with visits to school or other locations, may help to regularise the process in the mind of the person. For instance, the provision of more information about what the dental visit will be like and what the patient can expect may help to reduce the fears.

The results of this study support the argument of De Jongh, Adair and Meijerink-Anderson (2005), that keeping an individual with ASD informed about the treatment can have a significant positive effect on anxiety levels. This was also confirmed by the data provided by Participants 4, 8 and 10, who indicated that information and familiarisation were coping strategies they used to make the visits less stressful. Methods included using children's books (Participant 10), as well as verbal explanations at the time of the visit (Participant 4).

The results from the present study, however, suggest that verbal reassurances from caring dentists may be key to successfully calming children with ASD and this could mean that more severe physical restraints will be unnecessary. For example, some dentists adapted their

surgical environments to accommodate the ASD patient's reactions (such as by switching off the lights, or recognising the child's dislike of being touched). A study by Bultas (2012) also revealed the parental view that the dental surgery should contain appropriate toys. Together, these findings suggest there are various ways a dentist can avoid medication where, for example, this would not be necessary for TD children. The variance in methods may reflect the different approaches taken by individual dentists and their personal familiarity with children with ASD.

Parents of children with ASD and individuals with ASD were asked about what helped them cope with their dental anxiety. In this respect, various techniques, such as information and familiarisation, being with family, and even rewards, seemed to serve as ways to reduce the unpleasantness of the experience. These findings corroborate the ideas of Klein and Nowak (1998), who suggested that individuals with ASD may need to visit the dentist several times before receiving treatment in order to become familiar with the environment. This may be problematic for some dentists since this is not always feasible and may be time-consuming and costly. This may suggest that the responsibility for familiarising children with dental visits lies with the parents, who could, for example, accustom their child to sitting on a chair while lights are on and pretend to look at their teeth. As can be seen from the results, some parents took an active role in this respect, purchasing books (Participant 10) and ensuring their child would have the opportunity to watch their relatives undergo treatment first (Participant 2).

The complex relationship between parent and the child with ASD in relation to coping strategies and how these affect the child with ASD (Montes & Halterman, 2007) may indicate roles for other adults present during the treatment, such as dental staff, who could help to foster a relaxed and calm atmosphere. Pictorial impressions of adults remaining calm and relaxed may be helpful in these circumstances.

THEME 5: Other

Medication

Information was gathered on the medication that the ASD participants were taking. It is well recognised that people with ASD are more prone to be taking medication as opposed to TD individuals (Oswald & Sonenklar, 2007) and, as mentioned, medications may affect the development of caries (Marshall & Mancl, 2010). In the current study, this was identified by one mother (Participant 4) who reported that sugar in the medication could be affecting her child's teeth.

3.7 Conclusion

The study aimed to obtain a qualitative perspective on the experiences of individuals with ASD when visiting the dentist and in this respect it is considered that the methods were effective overall. The study was able to pick up on both direct statements of individuals with ASD as well as the opinions of their parents, which provided another dimension to the data.

The findings were interesting in relation to the individuals with ASD's experiences of pain since hyposensitivity has been recognised as a symptom of ASD in numerous studies. The statements were useful in yielding an insight into the patient's perspectives and in drawing conclusions about how the barriers to treatment may be overcome. Importantly, this study shows that dental anxiety in individuals with ASD is related to a number of stimuli associated with treatment, which may be made worse by the ASD disability itself. As confirmed by the TD literature, which is relevant to children with ASD as well, the present study identified issues such as fear of the unknown, fear of pain, general anxieties and changes in routine. Moreover, data in relation to the individuals with ASD's experience of pain were important since unusual pain responses have also been recognised as a symptom of ASD. The statements were useful in giving insights into the patients' perspectives and for drawing conclusions about how the barriers to treatment may be overcome.

This exploratory study helped the researcher understand some of the factors that prevent individuals with ASD receiving dental care and also flagged some possible causes for dental

anxiety, such as pain. These included fear of the unknown, family history of anxiety, previous negative experiences, sensory sensitivity, routine and familiarity, and worries about pain. As the literature has shown, dental anxiety can be affected in the TD population by overall anxiety, past negative experiences, negative thoughts about the dentist and parental anxiety, although sensory sensitivity is a cause that arises more specifically in the ASD population, due to the nature of the disability.

These factors will be combined with the findings of the second study, where dentists' views about dental anxiety will be explored. This will set the ground for the third quantitative study (Chapter 5) where factors identified by parents and dentist are tested to identify what factors best predict dental anxiety.

4 Chapter Four

Dentists and dental anxiety: A Qualitative Study

The current study considers dentists' views on the causes of dental anxiety, and how the behaviours of dentists can affect dental anxiety. In addition, it looks at interventions and treatment methods that dentists employ with individuals with ASD and how they compare with those highlighted in the literature.

This study was developed in order to complement the previous study (Chapter 3), which sought the opinions of individuals with ASD and their parents about their dental experiences. Dentists with varying experience of ASD were also asked about their experiences when working with anxious patients, with or without ASD, to identify the factors they thought were relevant in causing dental anxiety.

The current study also allowed the researcher to explore the interventions that dentist use with anxious patients. The attitudes and behaviours of dentists are critical in managing patients' anxiety, and research has shown that patients who consider their dentists to be angry or rude have greater levels of dental fear than those who visit co-operative and friendly dentists (Singh, Bhaskar & Rehman, 2015). It was also found that dentally anxious patients tend to have a negative attitude towards dentists (Singh et al., 2015).

Therefore, it is important that, in addition to being able to perform treatment to an appropriate standard, dentists must also be skilled at managing patients and their anxiety, in order that treatment is performed successfully and that the patient returns for further treatment when necessary (Armfield & Heaton, 2013). Developing a rapport of trust and confidence between the patient and the dentist is crucial. Communication is also important which can be both verbal and non-verbal, is also important because appropriate communication can reduce dental anxiety and promote positive attitudes towards oral health and care (Davies & Buchanan, 2013; Gupta, Marya, Bhatia & Dahiya, 2014)). The current study discusses, from the dentists'

point of view, the causes of dental anxiety and the methods that they use with individuals with ASD on a dental visit. Therefore, a literature search regarding best practice for children with ASD at the dentists was conducted, which revealed a wide range of possible methods that are employed by dentists when treating children with ASD (Johnson & Rodriguez, 2013).

In TD children, various psychological interventions have been shown to be effective due to their proficiency in decreasing dental anxiety (Folayan, Ufomata, Adekoya-Sofowora, Otuyemi, & Idehen, 2003). These interventions may be applied by either dentists or parents (Nelson, Sheller, Friedman, & Bernier, 2014). Interventions may be behavioural (relaxation, exposure, or systematic desensitisation), or cognitive (Cognitive Behavioural Therapy (CBT)) and in clinical practice these are often combined (Wide, Boman, Carlsson, Westin, & Hakeberg, 2013). CBT seeks to change the way people think about something and their behaviour in response to it (Marshman et al., 2016). For example, as this literature review suggests, anxious people tend to pay too much attention to threatening stimuli (Chalfant, 2011) and CBT may be a way to ensure such people do not become too focused on such stimuli and regard them as less threatening. Research shows that individuals with ASD can benefit from CBT as well as their TD peers. For example, in a study researching dental needle phobia among individuals with ASD, Lisowska and Zoitopoulos (2009) found that CBT was effective in treating their anxiety. This study measured both children and adults, which may have distorted the findings given that age is a factor that affects anxiety. Further, the study only examined a specific phobia: the use of needles. However, such interventions can be less effective for children with ASD as a result of their cognitive difficulties (Tager-Flusberg, 2007). As discussed, individuals with ASD have innate problems with processing the external world (Kuhaneck & Chisholm, 2012), including verbal communication (Kim et al., 2014). Amongst children with ASD, techniques have involved the use of visual stimuli, for which children with ASD have a notable preference (Isong et al., 2014; Rao & Gagie, 2006).

The literature suggests that common methods used for individuals with ASD are sedation and physical restraint. This may reflect a lack of understanding of how to deal with children

with ASD on the part of dental staff (Orellana, Martınez-Sanchis, & Silvestre, 2014). Other studies have confirmed the reliance on sedation, restraint or general anaesthesia (Loo et al., 2009). This suggests there is an important need to develop understanding and best practice in psychological interventions.

It has been suggested by Eli, Uziel, Blumensohn and Baht (2004) that corrective emotional experiences (such as the provision of clear information about procedures) can rectify anxiety issues for patients, thereby altering their perceptions for future appointments (Lin & Lee, 2007). For example, a number of techniques, such as stories, video modelling, and adjusting the dental environment to reduce sensory stimuli, may be employed to help children with ASD be exposed to dental procedures and environments in a gradual way, so that they are more comfortable at the time of the appointment (Nelson et al., 2014). It is suggested that actions of the dentists have a significant role in reducing dental anxiety; these actions involve the decisions they make regarding the treatment that will be used with their patients. However, previous literature provides information about treatments that work with TD children, and some that work with children with ASD, therefore, the current study seeks to collect dentists' views on what they believe are the best practices to use with children with ASD, and whether these practices are the same ones mentioned in the literature.

The main methodology used in this research is based on qualitative semi-structured interviews, which allowed for a primary focus on the experiences of the participants. Personal interviews were conducted with private dentists who had either some or little experience of working with children with ASD. Nevertheless, dentists who had limited experience with working with children with ASD had been taught in their dental training how to work with such children. Therefore, the input they provided was valuable and did not differ much from the dentists who had experience of working with these children. The interviews focused on the dentists' experience with the patients and their attitudes towards dealing with anxious patients when providing dental care. In addition, the interviews gathered information about interventions and methods that dentists use with individuals with ASD.

4.1 Research Questions

1. What are the common and general reasons that cause dental anxiety?
2. What are the approaches used by dentists and dental hygienists to manage dental anxiety in children with Autism Spectrum Disorder?

4.2 Methods

The qualitative method used in this present study involved semi-structured interviews. The interviews were administered to dentists with or without experience of working with children with ASD. For the reasons described in the first study, Section 3.1, a similar methodology was used.

An interpretivist epistemological position and a constructivist approach to the research methods were adopted in order to take account of the research aims and objectives. This study focused on considering the personal experiences and thoughts of dentists. The researcher's goal was to complement the first qualitative study, where individuals with ASD and parents of individuals with ASD talked about the role of the dentist in dental anxiety. It is understood by the researcher that the dentists' experiences and knowledge of dental anxiety and how they deal with it offer a unique, rich and immediate narrative for the research.

4.2.1 Sample

Participants were recruited through emailing private dental clinics. In addition, word-of-mouth was used, as well as direct advertising. Further contacts for interview were made through the help of the researcher's own dentist, who emailed the advert created by the researcher with information about the study to dentists that he believed might be interested in taking part. Full researcher contact details were provided and those who responded were provided with further information. The targeted sample was made up of individuals who met the following criteria:

1. Dentists with self-reported experience of treating anxious patients.

2. Dentists with self-reported knowledge about autism, even if they do not deal with patients who have ASD.

Table 4.1: Description of sample

Dentist	Gender	Country of origin	Direct experience with children with ASD	Experience with anxious patients	Received training in university about anxiety
1	Female	Netherlands	Yes	Yes	No
2	Male	United Kingdom	Yes	Yes	Yes
3	Male	Netherlands	Yes	Yes	Yes
4	Female	Netherlands	Yes	Yes	Yes
5	Female	United Kingdom	No	Yes	Yes
6	Female	Saudi Arabia	No	Yes	Yes
7	Male	Netherlands	Yes	Yes	No

As can be seen from Table 4.1, five of the dentists had specialised in the field of dentistry and special needs and had direct experience of dealing with special needs patients, including children with ASD. The remaining two had only limited experience but they had received training and so had acquired relevant knowledge. The difference between knowledge and experience is that knowledge consists of the facts, information, and skills acquired through education and includes the theoretical and practical understanding of a subject, whereas experience refers to a period of actual practice that could lead to gaining knowledge and skills. However, because it is difficult to have a dentist who is experienced in ASD in every geographical area, it was important to interview dentists who had limited or no experience but had knowledge about ASD. Nevertheless, it is worth mentioning that the dentists who had

limited experience possessed knowledge about autism and about dealing with anxious children, which made their contribution significant.

4.2.2 Ethical Approval and Consent

Ethical approval for the study was obtained from the University of Reading Research Ethics Board (Appendix 28, p.281). Each participant was asked to read an information leaflet outlining the study (Appendix 9, p. 240) and then sign a consent form (Appendix 10, p. 242), which detailed the purpose of the study and its procedures and stated that their participation was voluntary and that they could withdraw from the study at any time. The signed consent forms were stored in a locked cabinet and the participants were given a duplicate signed copy of the form to keep.

Each participant had to sign a consent form which stated that they had been given a copy of the participant information sheet, the opportunity to ask any questions about the study and had been given satisfactory answers, and also that the participant was aware that all personal information would remain confidential. It also stated that their participation was voluntary and that they could withdraw from the study at any time. In addition to getting written and verbal consent prior to interviewing, permission was also obtained in relation to the audio-recording of the interview.

4.2.3 Data Collection

The main methodology used in this research relied on semi-structured interviews, which allow for a primary focus on the experiences of the participants. Personal interviews were conducted. The interviews focused on the participants' experiences of providing dental care and their opinions about how to provide it.

The semi-structured nature of the interviews (see Appendix 8, p.239) allowed the questions to be guided but also permitted open discussion in some of the cases and allowed participants to include information that might not have been elicited by fully-structured questions (Holloway & Fullbrook, 2001). Interviews with the participants were audio-recorded

using a digital recorder and recording application on an iPhone. The resulting files were transcribed into text files for data analysis.

4.2.4 Development of Interview Questions

The interviews with dentists focussed on their knowledge and perceptions of dental anxiety in general, on what they think and know about dental fear in TD children, and what they think and know about dental fear in children with ASD.

The interview schedule draws on findings from existing literature on dental anxiety, although this process is also limited by the fact that most of it relates to TD children. It is also based on the literature available about the influence of dentists on dental anxiety. Several discussions were conducted with the researcher's supervisors about the questions used in the interview; questions focused on the dentists' experience, as well as their knowledge and opinions about how different factors affect the development of dental anxiety and how best to address them.

The first part of the interview schedule was about the dentist himself/herself and their general knowledge about dental anxiety and oral health. The second part addressed dental fears in TD children from a professional point of view. The third and final part addressed dental fear in children with ASD from a professional point of view.

A pilot interview was conducted with a dentist from Saudi Arabia who had limited experience of children with ASD. The pilot was carried out to evaluate the validity of the interview questions. Moreover, it was conducted to ascertain any changes that would be necessary to render the questions more constructive and to elicit more useful responses. The interview questions remained the same after the pilot study as the feedback from the Saudi dentist was positive and, as such, it was concluded that the second study interview schedule did not need editing.

4.2.5 Procedure

Once informed consent had been obtained, the interview session was initiated. Each interview lasted 30 minutes. The interviews were conducted independently with the dentist and took place over the phone. Telephone interviews demonstrate several advantages, such as participants being calmer and more comfortable speaking on the phone, being more likely to speak easily and share private information, and allowing access to participants from different geographical places (Novick, 2008). However, there are some disadvantages, including possible poor telephone network, lack of visual cues, the need to be brief in comparison to a face-to-face interview, and the chance of disruption of participants by events in their settings (Novick, 2008).

Interviews were audio-recorded using a digital recorder and an application for recording on an iPhone, and the resulting files were transcribed into text files for data analysis. After the interviews, the participants were thanked for taking part and the researcher instructed them as to how they could contact her if they had any further questions.

4.3 Data Analysis

The issues related to the analysis of the data in the second qualitative study also arose in relation to the first qualitative study. The second qualitative study also relied on the use of qualitative data collected via interviews and adopted the same approach to the analysis, namely, thematic analysis. The interviews were then processed in order to identify common themes running through the data as a whole (Braun & Clarke, 2006; Howitt, 2010). Full details on the approach adopted are contained in the data analysis section in the first study (Section 3.4).

In the present study, the researcher started by breaking the data down into codes. She developed these codes by looking for distinct concepts and categories in her data, which formed the basic components of the analysis. The researcher used coloured markers to distinguish different concepts and categories. For example, if interviewees consistently talked about methods and strategies they used with the patients, each time an interviewee mentioned it, or something related to it, the researcher would use the same marker. At the end of each analysis

the researcher ended with a transcript with different colours that highlighted different codes. These were then grouped into themes.

The researcher conducted the analysis of the data several times, which was also read and commented on by the researcher's supervisors. This resulted in edited and refined results each time. While only five main themes emerged from the first analysis, the researcher ended up with five main themes and 20 sub-themes. The final analysis therefore added a further and more in-depth dimension to the findings (Table 4.2, p.99).

4.3.1 Intercoder Reliability

As with the first qualitative study, the second qualitative study also uses intercoder reliability to gauge the accuracy of the qualitative text interpretation. Further details on the process applied are in Section 3.4.1 on intercoder reliability for the first qualitative study. As with the first study, the second study broke the text down into chunks and the themes identified by the researcher were agreed by the researcher's supervisor. It was then determined that one transcript would be coded, namely the responses from one dentist. It was sent to the supervisor to complete and then coded by the researcher.

The transcript that was chosen for the intercoder reliability was chosen randomly and was representative of the full research sample. The percentage agreement was calculated at 77.8% (reflecting 14/18 agreement and 4/18 disagreement, see Appendix 13, p. 247). Campbell, Quincy, Osserman and Pedersen (2013) point to research that has suggested that an intercoder agreement of 79 percent suggests it ensures a fairly high level of reliability and that it is acceptable to exceptional to have an intercoder reliability that varies between 70 percent and 94 percent. Smaller figures may be considered acceptable for exploratory research. As such, it is considered there was good agreement in the present research. As with the first qualitative study, the disagreements were resolved by discussion.

4.4 Results

The following information represents the results from the second qualitative study. Information was gathered concerning the dentists' views on how dental anxiety may be defined, in addition to their views on the importance of oral health, which are discussed below.

Respondents' Description of Dental Anxiety

Dentists were asked to describe or define dental anxiety. Three dentists said it was the worry of going to the dentist or carrying out any dental procedure (Participants 2, 5, & 6). Two described it as anticipating a negative experience (Participants 6 & 7). One dentist talked about it being the result of a past negative event (Participant 3) and another stated it was the fear of the unknown (Participant 1).

Respondents' Description of Oral Health

Dentists were also asked about the importance of oral health. All of them stated that oral health is very important, but there were several different reasons for its importance. Most of the dentists talked about the crucial impact that poor oral health can have on general health and well-being, such as good sleep, nutrition and quality of life (Participants 1, 2, 5, 6 & 7). It was also observed by one of the dentists that poor oral hygiene can cause gum disease (Participant 2). In addition, two of the dentists discussed the effect of oral health on social well-being and appearance (Participants 4 & 7).

Themes that Emerged from the Interviews

The interviews were analysed thematically and five main themes emerged. These were: parents, causes of dental anxiety, ASD and TD comparisons, methods and strategies used and other. Within some of these main themes, sub-themes were also identified (Table 4.2).

Table 4.2: Description of themes and sub-themes

	Main Themes	Sub- Themes
1	Parents	
2	Causes of dental anxiety	Past negative experience Negative stories or information from the outside Sensory sensitivity Pain Other forms of anxiety Fear of the unknown Understanding difficulties
3	ASD and TD	Difference between working with children with ASD and TD children Similar fears in individuals with ASD and TD Different fears in individuals with ASD and TD
4	Methods/strategies used by dentists with individuals with ASD	Individualised techniques according to the person's needs Strategies that are used with dentally anxious people Providing the patient with all the information about the treatment Building a rapport with the patient
5	Other	Things that are done by the patient to decrease anxiety

First Theme: Parents

The first main theme that emerged from the dentist data was the part that parents play in their children's experience of dental anxiety, whether TD children or children with ASD, and this was mentioned by all dentists. Given that the thesis focuses on children with ASD, parents were seen to participate in the child's dental visit to a significant degree; coordinating and carrying out the visit and explaining to the child that the visit is going to take place. As with all children, youngsters with ASD are more inclined to be influenced by their parents during this time. The results express the dentists' views about the role of the parents and the effects of parental anxiety on the anxiety of the child.

All of the participants discussed the role of parental behaviour and anxiety upon the TD child and the child with ASD's dental experience. Children learn behaviours and coping skills

from their primary caregivers (parents) and may easily be affected by temperamental changes in adults. Children may pick up on verbal or non-verbal cues and it is to be expected that parents will be anticipating the challenges the visit may present, given they know their child has ASD. As can be seen from the results, six of the dentists focused on how the parents behaved, which they felt was significant and influential upon the child's level of anxiety. The dentists discussed parental behaviour as being problematic and therefore having a negative impact upon the child. A dentist explained how the behaviour of an anxious parent can affect anxiety in the child:

> *When parents show too much concern, it always raises the anxiety of the child. I have seen this time and time again. A nervous or overly worried parent will always increase the anxiety levels in a small child.* (Participant 2)

Another dentist talked about children reflecting their parents' fears and anxieties:

> *Children whose parents are really afraid. They see this from their parents and they also get anxious.* (Participant 4)

A dentist described dental anxiety as being hereditary, as well as environmental:

> *We have proved that it's genetics that are responsible and it's also the experience I have. So even if people just know that they fear themselves, and they do all their best just to make sure that they don't influence in a negative way their own kids, even then you still might see that kids are fearful, parents are also fearful. So, I think it's also genetic as well. And also very often that they pick up communication off parents between themselves and among themselves which will also influence them.* (Participant 7)

Second Theme: Causes of Dental Anxiety

The present theme provides an insight into dentists' perceptions about causes of dental anxiety and their perceptions of their patients' subjective experiences as they are undergoing treatment. Some of the respondents considered anxiety to be related to past negative experiences, negative stories or information from outside sources, sensory sensitivity, and the sensation of pain. However, a number of dentists also suggested other reasons, which are also listed below as sub-themes: other forms of anxiety, fear of the unknown, and understanding difficulties.

Past Negative Experiences

Five of the dentists agreed that past negative experience is a significant cause of dental anxiety. As is suggested from the results, a past negative experience is generally related to feelings of

pain experienced during a previous visit. A female dentist from the Netherlands with experience of treating dental anxiety and children with ASD stated:

> *The cause of dental anxiety in children, having a bad experience, that happens a lot. So yeah, dentist starts drilling without local anaesthesia.* (Participant 4)

A male dentist from the Netherlands with experience of treating dental anxiety and children with ASD stated:

> *Past experience of course, so past experience in the dental clinic is causing an anxiety.* (Participant 7)

Another male dentist from the Netherlands with experience of treating dental anxiety and children with ASD stated:

> *That means that if you had a dangerous experience or like pain or something which you feel is dangerous, then you will remember it and gives you an anxiety trigger when you smell or see again the same trigger* (Participant 3)

As can be seen from the data, dentists raised various points that they thought could be a cause of dental anxiety, including poor practices by dentists or previous negative experiences. The dentists suggested these past negative experiences could be making later visits to the dentist a cause for concern for these individuals and raised the issue of conditioning: where a previous negative physical sensation leads to the forming of psychological apprehensions towards the trigger stimulus.

Negative Stories or Information from Outside Sources

Three of the dentists interviewed said that negative stories or information from outside sources were significant causes of dental anxiety. A patient is likely to have heard accounts from other people who have visited the dentist and picked up on their sense of discomfort.

Regarding the impact of information and stories heard from other people, a male dentist from the United Kingdom with experience of treating dental anxiety and children with ASD stated:

> *The most common cause is parents or friends enhancing the anxiety with negative stories and experiences, often exaggerating the facts.* (Participant 2)

A female dentist from Saudi Arabia with experience of treating dental anxiety but no experience of treating children with ASD stated:

> *Stories from older or other children or adults who have had negative dental experience.* (Participant 6)

A male dentist from the Netherlands with experience of treating dental anxiety and children with ASD reported:

> *Experiences from other people that the kids heard of. So they heard from family or peer group members, they talk about it, sometimes they see things, in movies or television. So it's very often also just a rumour they pick up and also just create fear already, without even having experienced themselves.* (Participant 7)

Other people's unpleasant experiences of other people will not necessarily mean the present patient will experience pain; however, it may well be a cause of psychological anxiety about the visit in advance. As the results show, dentists tended to believe that these negative perceptions were being passed on by friends, family and the media.

Sensory Sensitivity

Dental visits involve unusual experiences for each of the seven senses (including sight, taste and smell, for example) and this can cause specific problems for individuals with ASD. Four of the dentists suggested dental anxiety was due to sensory sensitivity. While Participant 6 spoke of the techniques they employed to avoid sensory sensitivity being an issue, Participant 7 spoke about considering the needs of individuals with ASD, suggesting that they viewed individuals with ASD as having unusual sensory integration, compared to other patients.

A male dentist from the Netherlands with experience of treating dental anxiety and children with ASD explained the different sensory system in an individual with ASD:

> *Autistic persons have a different sensory integration. So they react differently on to stimuli, and they do not describe, or they don't know how they differ, how they differentiate from us. So they are just different, the sensory system just functions differently very often, that's big thing.* (Participant 7)

A dentist explained that sensory sensitivity was problematic and identified various aspects of sensory concern:

> *The very high sensitivity of most children with autism is a complication. They are often quickly overstrung. And you have to touch the child with autism and that is a big*

> *problem for the child. Also they can have an extraordinary sensibility for smell and taste.* (Participant 1)

Another dentist identified sensory stimuli difficulties:

> *Like there are lots of stimuli during a dental treatment and lots of things happen, there's light, there's noise, there's a feeling, so that's what makes it really difficult for them.* (Participant 4)

Pain

Three of the dentists said dental anxiety was due to the sensation of pain. One of the dentists indicated that the problem was the existing pain causing the visit to the dentist in the first place, rather than the anticipation of further pain as the treatment begins. This may be because dental pain can arise suddenly and be relatively severe and therefore the dentists considered this pain to be the cause of dental anxiety. The other dentist suggested dental anxiety was due to the sensation of pain, although it is unclear whether this related to existing pain or the anticipation of pain during treatment.

A male dentist from the Netherlands with experience of treating dental anxiety and children with ASD observed:

> *Kids are fearful because they are in pain already. So I think experiencing pain, on itself in the mouth is a reason for kids just to refuse other people to even look in the mouth.* (Participant 7)

A male dentist from the Netherlands with experience of treating dental anxiety and children with ASD stated:

> *Child feels pain and gets anxious, as an example.* (Participant 5)

Other Forms of Anxiety

Four of the dentists interviewed considered dental anxiety to be related to the patients' pre-existing feelings of general anxiety. Regarding the existence of other forms of anxiety, a female dentist from the Netherlands with experience of treating dental anxiety and children with ASD stated:

> *They have other fears in addition.* (Participant 1)

A male dentist from the Netherlands with experience of treating dental anxiety and children with ASD stated:

> *There's always a little percentage of people and also children, which have anxiety disorder primary.* (Participant 3)

It is unclear from the data how the dentists came to these conclusions; it could be the result of general impressions about the personalities of their patients as they visited their surgeries. It is also to be expected that the dentists would have had the opportunity to compare the behaviours of patients as different individuals who come for treatment and notice differences between them.

Fear of the Unknown

One of the themes explored by the present study is the impact of the 'unknown' on dental anxiety. Fear of the unknown is a specific factor that causes problems for individuals with ASD, who are likely to be a small minority of the dentists' overall patient population. During the study, only one dentist suggested that fear of the unknown was a factor. A male dentist from the Netherlands with experience of treating dental anxiety and children with ASD stated:

> *It's, most of the time, that what is going to happen is not clear, or there is no prediction of it, in their treatment.* (Participant 3)

This is an important finding because fear of the unknown is a significant variable for individuals with ASD and their anxiety about dental treatment. This research indicates there could be a widespread lack of knowledge about the specific causes of dental anxiety in individuals with ASD.

Understanding Difficulties

A visit to the dentist involves a degree of new information and behaviour, such as the need to sit in the chair and keep still while work is completed, even if pain is experienced. Patients will also be interacting with the dentist, as the dentist guides the patient, for example, by asking them to perform a particular action (such as keeping their mouth open), or to explain the feeling they are having (such as a sense of pain in a particular location). As such, the communication

between the patient and dentist is critical to ensuring the treatment is performed properly and without accident.

Only one of the dentists suggested that dental anxiety in individuals with ASD is caused by their difficulty in understanding information. A male dentist from the Netherlands with experience of treating dental anxiety and children with ASD explained the different sensory system in an individual with ASD:

> *The problem is people with autism is that they have the information. And with information I mean on all levels, not only speaking, but everything that they see, feel, smell, they cannot comprehend. They cannot make a current picture of it in their mind* (Participant 3)

From the data, it appears the dentist was aware that individuals with ASD have impaired abilities across a wide range of social communicative areas.

Third Theme: ASD and TD

As mentioned, five of the participating dentists had experience working with individuals with ASD. Clearly, people with ASD are similar to other patients in terms of their dental problems. The difference mainly lies in their reactions to the visit and treatment and the heightened sense of anxiety that individuals with ASD usually tend to feel.

This part of the data was important for the study in terms of the overall research questions since it focused specifically on the dentists' understanding of individuals with ASD and their unique requirements. The data was classified into four further sub-themes, namely, the difference between working with ASD and TD children, similar fears in individuals with ASD and TD, different fears in individuals with ASD and TD, and reasons for greater levels of dental anxiety in patients with ASD.

Difference between Working with patients with ASD and TD patients

Six of the dentists gave responses regarding the differences they perceived when working with ASD and TD patients. As will be seen from the data, all the respondents considered a different approach to patient management would be necessary when dealing with children with ASD.

The responses also varied widely, which reflects the different personal approaches taken by each of the dentists, which is considered relevant qualitative data for the present study.

A dentist discussed their behaviour when dealing with individuals with ASD:

> *You will be very alert to what you say and what you do. Say what you do and do what you say. Changes in your behaviour, the environment or your treatment will be disastrous.* (Participant 1)

A dentist recognised that different levels of ASD severity will affect interaction:

> *It depends on the degree of autism. I do have to take a lot more time explaining and interacting. I try to engage the child in the process.* (Participant 2)

A dentist suggested a very different set of behaviours are necessary where an individual has ASD:

> *It's different in the sense that you need to be more humble. So with your average child, it's very often we have got a kind of an extrovert style. And with autism it's better just to be in the introvert mode. So you need to have to be ... don't give too many impulses. So wait for the autistic child, let them ... the guidance should be soft.* (Participant 7)

Similar Fears in Individuals with ASD and TD

Four of the participants gave responses as to whether they believed patients with ASD and TD patients expressed similar types of fears when visiting the dentist. The results suggest that the dentists considered that both groups generally have similar fears. It is, however, unclear whether the dentists consciously recorded the differences they experienced between these patients at the time and therefore this data reflects their general impressions, which they have developed from experience.

A dentist suggested there was not a significant difference:

> *I do not really think there is too much difference as we still face the same challenges with children and dental treatment.* (Participant 2)

A dentist suggested there was a similarity in practice with children who had dental phobia and recognised different levels of ASD severity:

> *Yes, they can be compared to children with dental phobia. But as mentioned previously this depends on the level of autism.* (Participant 5)

Another dentist suggested the fears were the same:

> *The reason is the same, but for people with autism, it's quicker.* (Participant 3)

Different Fears in Individuals with ASD and TD

Conversely, data was also gathered as to whether dentists thought ASD and TD patients presented different fears. It was to be expected that individuals with ASD may have more fears, at an increased level of severity than TD patients. Only one participant gave a response in this respect. From the data, it appears the dentist noticed that treating patients with ASD was a far greater struggle:

> *We don't know. I don't think we can know really. But very often we don't get that far. But of course it helps to know what the level of autism is, but very often you won't even get to, for instance, doing a filling because it's just too much. So the answer is no, it's not the same, because they react already so heavily on certain sounds or tastes in the mouth, that it can't be seen as normal work at all. So it's different. It's different.* (Participant 7)

Fourth Theme: **Methods /Strategies used by Dentists with Individuals with ASD**

Given the occurrence of anxiety during dental treatment, the present study collected information about the methods used by dentists to reduce this problem. As may be seen from the participant table (3) above, only five of the seven dentists included in this study had received training for disabled patients. All of them had experience with anxious patients (as per the inclusion criteria for the study) but only five had experience with individuals with ASD.

A number of techniques are currently employed in professional settings to reduce dental anxiety and the sub-themes identified within this category include: individualised techniques according to the person's needs, strategies that are used with dentally anxious people, providing the patient with all the information about the treatment, and building a rapport with the patient. This qualitative data has enabled the study to identify practical and effective solutions to the problem of dental anxiety, which may be used to improve dental treatment in the future.

Individualised Techniques According to the Person's Needs

Given that dental problems affect anyone, dentists can expect to come into contact with a range of individuals with extremely different personalities and intellectual abilities. Some may place a lot of trust in the dentist and be happy for them to undertake the work as quickly as possible. Others may wish to know everything that the dentist plans to do, and the extent to which the dentist can meet these personal needs will affect the patient's level of anxiety about the

treatment. As such, dentists need to tailor their approach to the individual patient and this will be particularly important where the patient is an individual with ASD, since the patient is likely to have a highly individualised set of behaviours and capacities. Six of the seven respondents spoke of this need to tailor their approach to the individual patient. As such, all five of the dentists with ASD experience mentioned this need, as well as one dentist who did not have experience with individuals with ASD. This suggests this approach is considered particularly useful by dentists and reflects a general approach to dental practice. A dentist stated their approach to individualised treatment:

> *I use an individualised technique according to the person.* (Participant 1)

Another dentist recognised they had to modify their approach when dealing with individuals with ASD:

> *I try to work with the patient as opposed to following a set of rules. You do have to change your approach dependent on the child and their learning or understanding capacity.* (Participant 2)

Another dentist recognised how unique a patient's needs may be when they have ASD:

> *It's very, very, very much individualised. Because if you have one pill for one disease, it's simple for one who is going to give this treatment. But if you have autism you have to really do homework. It's not so simple.* (Participant 3)

Strategies used with Dentally Anxious People

All the participants discussed strategies they used with patients who are dentally anxious. As mentioned, all of the participants had experience working with anxious patients and considered dealing with anxiety to be a regular part of their practice. This part of the study gave the participants an opportunity to describe the methods they personally employed and, as can be seen, the techniques used varied considerably. Some of the participants focused on the need to evaluate the individual and take their personal needs into account: for example, Participant 1 suggested dentists had to '*be calm and take the anxious person seriously*'. Another mentioned ways to develop a trusting relationship:

> *This was to be on their level, clear and predictable … the base of this trust the anxiety will be less, and they can manage that I treat them.* (Participant 3).

Another dentist explained that he relied on pictures to treat his patients with ASD:

> *I use pictures a lot with the children with autism. So I make pictures of all steps of treatment and so they're, yeah, they're visualising, it's something I do with autism children. And yeah, that's what I do mostly.* (Participant 4)

Another dentist discusses various potential techniques:

> *The best way is to learn behavioural management techniques (non-pharmacological along with pharmacological). For example:*
> *1-Tell-Show-Do*
> *2-Positive Reinforcement*
> *3-Distraction*
> *4-Building a Trust Relationship with Both the Child and Parent*
> *5-The Use of Inhalation Sedation*. (Participant 5)

A dentist described the importance of tailoring the communication to the individual:

> *This was to be on their level, clear and predictable … the base of this trust the anxiety will be less, and they can manage that I treat them*. (Participant 3)

Providing the Patient with all the Information about the Treatment

Four of the participants stated that they provided information to their patients as a way of reducing the anxiety they experienced. As a specialist profession, dentists expect that patients will be unaware about the exact procedures to be used during the treatment. Information is important to explain what treatment is going to be performed, why it is necessary and what degree of pain the patient can expect to feel. As can be seen from the results, responding dentists focused on the process of communication, suggesting that the way the dentist explained the information was important.

One dentist emphasised the importance of explanation: '*Give explanation of what happens'* (Participant 1); another of giving patients enough time to understand, stressing the importance of allowing time to ask as many questions as needed (Participant 3). One dentist elaborated on what should be communicated: '*Explain everything to the patient, take him through the details of the procedure as appropriate for their age and knowledge. Try to show the patient as much as possible all the instruments to be used and what's to be done with them'* (Participant 2)

A dentist mentions the transmission of information:

> *When parents show too much concern, it always raises the anxiety of the child. Give explanation what happens*. (Participant 1)

Another dentist gives details about what should be communicated:

> *Explain everything to the patient; take him through the details of the procedure as appropriate for their age and knowledge. Try to show the patient as much as possible all the instruments to be used and what's to be done with them*. (Participant 7)

Building a Rapport with the Patient

Three of the participants suggested the importance of building a rapport with the patients as a way to reduce anxiety. Since most patients visit the dentist infrequently and may even decide to visit different dentists, the opportunity to build a rapport may be limited. For this reason, dentists will have to find ways to achieve this relatively quickly as the visit is taking place. As can be seen, two of the participants spoke of the need to make adequate contact with the patients (Participants 3 and 7) and one spoke of the importance of trust (Participant 1).

A dentist discussed the interactions he had with people who have anxiety:

> *I make a connection with the people, like they tell me that they're anxious. And I understand them and sit with them, they have the feeling that I hear them.* (Participant 3)

And another dentist concurred:

> *The way we are successful with children is that we build a contact with the child and you have to stay in contact … the basis is stay in contact a rapport as we say, rapport with your patient, that's the basis.* (Participant 7)

Fifth Theme: Other

Finally, the study collected further information that could not be categorised under any of the previous themes. Therefore, a sub-theme was developed to reflect things done by the patients themselves to decrease their anxiety. Only one participant provided data in this respect. This may suggest that dentists do not often see patients taking steps to reduce their own anxiety.

A dentist described how individuals could help themselves become less anxious:

> *Oral health in children has improved a great deal in recent years. Children attending from a young age build rapport with the dentist and familiarize themselves with the dental environment. They are much less afraid than they once were. Some children bring their headphones or something, but that's, yeah*. (Participant 4)

4.5 Discussion

This second qualitative study shows that anxiety is a routine part of dental practice, that dentists are aware of it and are accustomed to dealing with it. The majority of dentists interviewed had specific experience dealing with individuals with ASD, although this was not universally the case for the present sample. Dentists were asked if they regularly treated individuals with ASD. The dentists with experience of individuals with ASD did not differ significantly from those without, except with regard to the techniques they mentioned they used with patients with ASD. As some dentists had less experience with individuals with ASD than others, they provided more limited answers and information regarding this aspect, which means that it is not sufficient just to have knowledge about dental anxiety, it is important to understand autism and the needs of the individual with ASD as well.

Dentists' behaviours can have a significant effect on the level of dental anxiety that an individual with ASD experiences (Singh, Bhaskar, & Rehman, 2015) and this can be seen from the results of this second study. The following discussion examines the qualitative findings from the dentists' responses. The factors that cause dental anxiety are then examined in the third study and complement the findings from the first qualitative study. As listed under the first theme of the present study, the dentists put forward various reasons why they believe dental anxiety occurs.

First Theme: Parents

There is a general consensus among all dentists that parents can significantly influence a child's psychological state, and that has been noted in previous literature (Brooker et al., 2015) and the influence of parents emerges as a main theme within the second qualitative study. The present study reveals a number of aspects to this factor. For example, Participant 4 suggested that parents who are anxious model anxiety for their children. Participant 2 said that dental anxiety can be caused by specific parental behaviours, such as showing too much concern. Participant 7 mentioned the issue of modelling but also genetic factors.

The psychological effect of parental anxiety is discussed in the present literature review (Lazarus et al., 2016; McAdams et al., 2015), as are the genetic and hereditary aspects (Al-Biltagi & Sarhan, 2016; Muris, van Brakel, Arntz, & Schouten, 2011;): some of the participants in the first qualitative study also mentioned that they had noticed anxiety in their relatives. However, while some parents in the first study evidenced their own personal anxieties, none of them suggested this as a cause of their child's anxiety.

The comparison between the two sets of qualitative data from the first and second studies enables the present study to obtain multiple perspectives on the causes of dental anxiety and to illustrate attitudes and beliefs about dental anxiety, which are important in relation to the steps that can be taken to remedy them. The dentists do, however, confirm the importance of family support as a coping strategy for dental anxiety, which is discussed in the literature (Hall & Graff, 2011; Hastings & Johnson, 2001; Higgins, Bailey & Pearce, 2005). Family support is also mentioned as a factor.

Participant 1 criticised certain parental behaviours; for example, that it is wrong for parents to suggest there would be no pain when this may not be totally correct. This is a complex finding, since it depends on a parent's knowledge about a dental procedure and further research could examine the extent to which (correct and incorrect) parental reassurance either increases or decreases dental anxiety for a child. Clearly, parents have a significant influence on children's knowledge and beliefs about dental visits and this is examined in greater depth in the quantitative study. The third study seeks to provide a comparison of the association between parental anxiety and dental anxiety for both the ASD and TD groups.

Second Theme: Causes of Dental Anxiety

Participant 3 spoke of the cognitive associations that can be triggered as a result of previous bad experiences and the majority agreed that previous negative experiences are problematic. These findings are consistent with existing literature (Armfield & Heaton, 2013; Beaton, Freeman, & Humphris, 2014), as well as the findings from the first study. Past negative

experiences leave a psychological imprint upon the mind of the individual and this reflects the relationship between physical pain and psychological concerns about pain.

The impact of past negative experiences is commonly identified as a factor that causes dental anxiety, evidenced in the second qualitative study, and this variable is therefore examined directly in the quantitative study that follows. The third study examines the correlation between past negative experiences and dental anxiety for both ASD and TD groups.

The transmission of untrue or exaggerated information about dental visits is an aspect discussed under the sub-theme of 'negative stories or information from the outside'. Dentists spoke of the role that parents, friends and other adults can play in spreading negative information about dental experiences. This process has been explained as a feature of social interaction, where attitudes towards dental care reflect learned behaviours (Nagaraj, Ganta, Yousuf, & Pareek, 2014; Sharma, Mallaiah, Margabandhu, Umashankar, & Verma, 2015). Importantly, it has been suggested that information transmission is problematic where unquestioned false ideas that are not based on reality serve to mislead patients about the visit, which makes it more challenging for dentists to offer satisfactory treatment. This is an interesting sub-theme because it was not mentioned by individuals with ASD or parents of children with ASD in the first qualitative study as a factor that can affect the development of dental anxiety.

Further, the present research has reviewed several studies on the causes of dental anxiety and there are very few which deal with the issue of information transmission and its effects on dental anxiety (Beaton et al., 2014; Carrillo-Diaz et al., 2012; Paryab & Hosseinbor, 2013). As such, the second study provides further insight into the potential causes of dental anxiety from the perspectives of the dentists.

Since the dentists were not asked specifically about sensory sensitivities, even though they were implied in the questions, they did not speak much about them. Nevertheless, this 'finding' contrasts with the findings from the first qualitative study that these are important variables. One dentist did know that sensory sensitivity was a particular problem for individuals

with ASD. Only Participants 4 and 7 indicated their awareness of individuals with ASD having a different type of sensory sensitivity to TD patients. Participant 6 said they adopted an overall approach of trying to make the procedure as painless as possible. Participant 3 suggested that individuals with ASD 'cannot comprehend' and, while this may be true in some cases (Moraine, 2015; Shroff, 2015;), it is not universally the case (Geschwind & State, 2015; Thompson, Davis, White, & Ollendick, 2014). This dentist's view may have been affected by the severity of ASD that patients had presented in the past and also by the fact that the researcher asked open-ended questions, which did not address sensory sensitivity in particular. These results suggest that, while dentists have experience with anxious patients, further professional education could help them become more adept with dealing with individuals with ASD (Barnes, Bullock, Bailey, Cowpe, & Karaharju-Suvanto, 2012).

Considering that seven dentists were interviewed, this might suggest a lack of awareness of the causes of dental anxiety in the ASD population. However, this would require wider research to substantiate. Nonetheless, awareness of the needs of patients with ASD is important because lack of this awareness can serve as an important barrier to treatment of this population.

Although the interview schedule did not raise the issue of sensory sensitivity directly to dentists, it did ask them how treating children with ASD differed from TD groups. Given a number of questions were asked about treating children with ASD, it is noticeable that most dentists did not raise this as an issue. Sensory sensitivity is examined further in the third study.

A number of the professional respondents considered that anxiety stems from the physical pain caused by the current dental problem. One dentist considered this as related to the pain that leads to the requirement for a dental visit (Participant 7), while another simply linked the sensation of pain to anxiety (Participant 5). This is in accordance with the literature, which finds that children who experience painful dental problems feel significantly higher levels of dental anxiety during the visit (Ramos-Jorge et al., 2013).

In this respect, the dentists in the qualitative study commented on their concerns that other dentists within the profession may be causing patients pain during treatment and, thereby,

could be contributing to further dental anxiety later. Some dentists spoke of poor practices by other dentists, such as not applying anaesthesia before drilling (Participant 4). In this respect, the literature finds that drilling, as well as injections, can be the main experience that triggers dental anxiety (Appukuttan et al., 2013) and studies suggest that anaesthesia for young patients, in particular those with disabilities, is routine practice where there is a risk of fear or anxiety (Zhao, Deng, & Yu, 2014).

Poor professional standards by dentists was not an aspect raised by the participants in the first qualitative study and this may suggest they did not consider their dentists to be the cause of their dental anxiety. However, the individuals with ASD and their parents said they had witnessed things like excessive amounts of blood during the previous treatment of family members and this could mean their dentists made some mistakes during the treatment. The differences between the worries and anxieties held by ASD and TD individuals are further tested in the third study.

The second study also reveals that dentists considered the pain from the existing dental problem to be the cause of dental anxiety, although the sample in the first qualitative study suggested the problem was more due to the fears and worries about the pain that could occur. As such, the present second qualitative study opens up further dimensions to the findings on the causes of dental anxiety.

Some dentists suggested that patients with dental anxiety and ASD have other co-existing forms of anxiety, which adds weight to the view that existing anxiety affects dental anxiety. One dentist suggested that people with dental anxiety have other fears as well (Participant 1); another one said that a percentage of patients with dental anxiety always have anxiety disorder as a primary disorder (Participant 3).

Although the first study recognises that individuals with ASD with dental anxiety often have anxiety about other things as well, none of the first qualitative study participants actively suggested their other anxieties were the cause of their dental anxiety. These findings as a whole may be explained by the dentists being able to give a more objective view of the individual's

personality, although it could also be due to simply to speculation; the dentists did not undertake any particular examination of their patients in terms of their pre-existing anxieties. Further, these comments from the dentists obscure a number of overlapping issues: the wide variety of anxiety sub-types, the distinction between fears and anxieties, as well as the frequency with which anxiety disorders occur comorbidly with ASD

The literature finds that general fear is associated with dental anxiety (Bruin et al., 2007; Klin et al., 2005; Klingberg & Broberg, 2007; MacNeil, et al, 2009; White, Oswald, Ollendick, & Scahill, 2009) and this is also mentioned as a variable by the participants in the first qualitative study.

The relationship between other anxieties and dental anxieties is also found in the TD population and this forms the focus of most of the literature in this field to date. However, research finds that individuals with ASD are more prone to endure other anxiety disorders as opposed to TD individuals (Bruin et al., 2007; Klin et al., 2005; White et al., 2009). Therefore, it will be interesting to examine the importance of existing anxiety to dental anxiety by comparing TD and ASD groups in the third study.

Only one of the dentists mentioned fear of the unknown as a cause of dental anxiety. Given that this is an important factor for individuals with ASD, these results suggest either that dentists do not have adequate understanding of this cause of dental anxiety, or that the interview question did not address this matter in an adequate way. Participant 3 noted that this factor arises where the procedure is 'not clear' and also raised the issue of patients needing to predict what will occur. This factor is discussed in the literature in terms of the intolerance of uncertainty in individuals with ASD (Wigham et al., 2015), as well as the insistence on sameness (Gotham et al., 2013), although no recent literature has studied this issue in the dental context. Therefore, the present study has identified an important area for further research in the ASD dental context.

One dentist mentioned that individuals with ASD have difficulties with understanding and communication (Participant 3). This is an expected finding, given so much of the literature

has discussed these types of problems in the ASD population. The dentist who answered this question suggested that individuals with ASD have deficits in a wide range of communicative skills, which is consistent with findings in the literature. For example, research has shown individuals with ASD often display unusual social behaviours (Kim et al., 2014) and have problems with the processing the external social stimuli (Baron- Cohen, 2009; Grove, Baillie, Allison, & Baron-Cohen, 2013).

Current research recognises that there are varying levels of ASD severity, which means that not all individuals with ASD display challenging symptoms. Communication is a skill that may be learnt during professional training, but it is also something that is developed through practice (Davies & Buchanan, 2013; Gupta, Marya, Bhatia, & Dahiya, 2014; Moosavi, Narimani, & Vosugh, 2015), and it may be that dental practice needs to improve understanding of communication difficulties in patients with ASD.

Third Theme: ASD and TD

The third theme to emerge addresses the differences between individuals with ASD and TD individuals. This data helps to identify that individuals with ASD have a different and more challenging experience when visiting the dentist and this aspect is later tested in the third study. The results show there is sufficient general awareness among dentists that tailored measures are necessary to adequately treat those individuals. This is in accordance with the literature that emphasises the importance of the dentist's approach during the visit in terms of managing dental anxiety (Armfield & Heaton, 2013). The dentists discussed this difference in terms of the behaviours and attitudes necessary to deal with patients with ASD, in particular, and the sub-themes that emerged in this area include differences between working with children with ASD and TD children, whether ASD and TD hold similar or different fears and, finally, their opinions as to the reasons for increased levels of dental anxiety in individuals with ASD.

As the data shows, six of the dentists in the present study recognised that individuals with ASD require particular treatment. Participant 1 said they, as dentists, are careful about what they say and how they behave, which is consistent with the literature that finds that the

dentists' communication approach impacts on dental anxiety (Davies & Buchanan, 2013; Gupta, Marya, Bhatia, & Dahiya, 2014).

Participant 2 referred to the importance of explaining the treatment to the individual, which is discussed in this study in terms of potentially helpful interventions. For example, research shows that providing information about what the visit will involve can help to reduce dental fear (Eli et al., 2004) and can also make patients feel more comfortable during the appointment (Nelson, Sheller, Friedman, & Bernier, 2014). Participant 7 discussed his personal behavioural style and why he thought it necessary (Singh, Bhaskar & Rehman, 2015; Zhou, Cameron, Forbes, & Humphris, 2011).

The second and third sub-themes concern whether or not individuals with ASD hold similar or different fears to the TD population. The results show that four dentists considered them to hold similar fears, although one considered them to be different. Research shows that individuals with ASD have both higher levels and different types of fear and fear responses than the TD population (Cagetti et al., 2015; Farrugia & Hudson, 2006) and that the reasons for the anxious response may be different (Hollocks, Ozsivadjian, Matthews, Howlin, & Simonoff, 2013). This factor is tested in the quantitative study that follows.

Fourth Theme: **Methods /Strategies Used by Dentists with Individuals with ASD**

A number of participants recognised that treatment of patients with ASD may be more difficult and that different behavioural approaches may be required and modified, depending on the severity of the disability. The second study identifies a number of strategies currently adopted by professional practice to manage dental anxiety and, in this respect, reveals a wide range of different techniques, which have generally been endorsed by the literature. Some of these strategies were mentioned by dentists who had experience with ASD; some were mentioned by dentists who did not. A majority of dentists spoke of the importance of communication, which involves building a rapport, as well as transmitting information. In this respect, research shows that a greater understanding of dental practices reduces levels of anxiety levels (Appukuttan et al., 2013). The present study also identifies the related theme of

understanding difficulties and this covers both verbal and non-verbal communication (Participant 1).

Given communication is so important to reducing anxiety in dental contexts, this may be particularly problematic, since children with ASD typically have problems with verbal communication (Dua et al., 2016). This study identifies that, in these circumstances, dentists often rely on visual cues, such as pictures or social stories, which is a method mentioned by some of the participants and which has been found particularly useful for children with ASD (Isong et al., 2014).

The results suggest that dentists are aware of the importance of communication, although further research could investigate this issue in relation to individuals with ASD in more depth.

Fifth Theme: Other

The final point that is raised by the second qualitative study is a coping strategy used by the dentist's patient themselves to reduce their own anxiety. Coping strategies were not part of the interview schedule presented to dentists, so this may explain why only one dentist commented on the subject. Dentists were, however, asked about how they managed their patients with dental anxiety. Participant 4 mentioned the importance of children familiarising themselves with the environment and also that children sometimes bring things with them, such as headphones.

While the importance of familiarising an individual with the dental environment is discussed in the literature (Nelson, Sheller, Friedman, & Bernier, 2014), none of the papers found during the literature review mentions the value of personal items, such as toys or modern technology, nor was this factor raised by the participants in the first study. Personal items may serve as a source of comfort for children who are anxious (Kebriaee et al., 2015) and although this does not form the focus of the present research, it is considered a useful finding revealed by the present study in terms of coping strategies.

4.5.1 Comparing the Two Qualitative studies

This section will present a discussion on the main comparisons between the first and second qualitative studies. Since the studies gathered data from different groups of participants, each was able to collect some valuable data that was not covered by the other. For example, the professional dentists in the second study were in a position to give their opinion on the oral health of individuals with ASD, although this issue was not covered in the first study. Similarly, dentists were able to compare aspects of treatment for ASD and TD groups, such as the similarity and differences between the fears they held, and the differences in the approaches taken to their treatment. Again, the ASD participants in the first study were not in a position to provide information on these subjects.

Fear of the Unknown

One of the main issues to emerge in the studies was fear of the unknown (Wigham et al., 2015). Fear of the unknown was raised by nine of the participants in the first study, although only one dentist saw this as an issue in the second one. Other dentists did, however, allude to this factor when discussing the need to explain the treatment to patients with ASD (Participant 2). The comparison between the findings of the two studies demonstrates that there may be a lack of awareness among dentists of the importance of this variable. As such, this finding may contribute to the knowledge of the professionals of this important aspect.

The dentist who mentioned fear of the unknown (Participant 3) seemed to believe it is based on a lack of clarity about dental procedures. This was confirmed by the Participant 12 from the first study, who said the issue was '*not knowing what's going to happen*' at the surgery. However, as other responses from the first study and the literature have shown, fear of the unknown in individuals with ASD is more far-reaching than simply not knowing what will happen during treatment. Unusual activities are often considered to be a change in ordinary routine which is notoriously problematic for people with ASD (Boulter, Freeston, South, & Rodgers, 2014).

Pain

The issue of pain was raised by participants in both the first and second studies. The participants in the first study mentioned they had a fear of pain (Participants 4 and 5), while others pointed to particular items that could cause them pain, such as the drill (Participant 2). In the second study, one dentist said anxiety was generated by the pain their patients were feeling before the visit (Participant 7). As such, a comparison between the studies shows that the issue of pain can relate to the physical sensation, as well as the anticipation of pain. Individuals with ASD generally experience a heightened sensitivity to pain (Courtemanche & Black, 2016) and their difficulties in communication can make it hard for them to express the pain they are feeling (Delli et al., 2013; Dua et al., 2016). As such, the psychological fear of pain is also a significant factor for individuals with ASD.

Avoidance

The first study showed that a large proportion of individuals with ASD try to avoid visiting the dentist. This point, however, was not raised by any of the dentists in the second study, possibly because dentists are unaware of the decisions made by their patients to avoid treatment. As research has shown, individuals with ASD often avoid those tasks or situations that represent a change in their routine (Wigham et al., 2015). Accordingly, avoidance may be more problematic in the older population than the younger, where routines will be managed by parents. This is supported by the statement of Participant 1, who said they stopped visiting the dentist, '*as soon as they had the choice*'.

Routine

As discussed, the issue of routine is important to dental visits for individuals with ASD (Kim et al., 2014). This emerged as a separate sub-theme in the first study, although was not mentioned by any of the dentists in the second. This adds weight to the suggestion that dentists may not be fully aware of the peculiarities of ASD and the needs that individuals with ASD have in particular.

Negative Thoughts about the Dentist

Negative thoughts about the dentist have been shown to affect both the ASD and TD populations (Farrugia & Hudson, 2006). With respect to the two sets of data in the present research, negative thoughts about the dentist emerged as an issue in the first study, although it was not raised in the second. Again, this may be because negative thoughts are personal to the dental patients themselves and a dentist cannot know what is going on in another person's mind. Similarly, the sub-themes of 'Feeling about the dentist/dental visits' and 'Effect of poor care of teeth' emerged in the first study, but not in the second. The first study raised the issue of feelings about the dentist, with some participants saying they disliked the process (Participant 4). This, however, was not mentioned by any of the dentists.

Negative Information Transmission

Dentists in the second study did, however, comment on the issue of negative information transmission, which they felt was problematic. Although relatively understudied in the field of ASD, negative information transmission from parents and peers has been found to have an impact on dental fear in the TD population (Beaton et al., 2014). Dentists in the second study felt negative information transmission encourages patients to hold negative beliefs about dental visits. Negative information transmission was not, however, mentioned by the participants in the first study. The differences between the studies in this respect may reflect the ability of each set of participants to speculate on the beliefs and opinions held by others.

Previous Negative Experiences

Previous negative experience was raised in both studies as a factor that causes dental anxiety. As with negative information transmission, there is relatively scant literature on the impact of previous negative experiences for individuals with ASD in the dental context. This may be because dental fear research has focused on the particular features of ASD disability, rather than those issues that affect both the TD and ASD population generally. The issue has been studied in the TD population, with the study by Humphris and King (2011) finding that those who have previous negative experiences are two and a half times more likely to

experience high dental anxiety than those who have not. That study also found that local anaesthetic injections are the most problematic issue in this respect (Humphris & King, 2011).

Both sets of participants considered previous negative experience to be a significant factor. The dentists related this issue to past negative experiences of physical pain. For example, Participant 4 in the second study suggested problems could arise if a dentist used the drill without anaesthesia. The participants in the first study, however, described distressing experiences they had witnessed, such as excess blood (Participant 1), a tooth falling out (Participant 8) and the need to repeatedly inject anaesthetics (Participant 4). Participant 3 in the second study said it was the act of remembering such events that produced a response of dental fear and this supports the statements of the first study respondents.

Family Members

In terms of the impact of family members, the first study revealed there is a significant link between parental anxiety and the anxiety of children with ASD. Some dentists suggested anxiety was transmitted from parent to child through modelling (Participants 2 and 4) (Zaidman-Zait et al., 2014). Another one considered that genetic and hereditary factors also play a role (Participant 7). As mentioned, both the behavioural (Coric et al., 2014; Stein Polido, & Cermak, 2013; Themessl-Huber et al., 2010) and biological impacts (Mazefsky et al., 2008) of dental fear have been discussed extensively in the literature.

Participant 2 in the second study suggested that parents often exhibit too much concern, which raises the child's level of anxiety. This was confirmed by Participant 5 (a parent) in the first study, who said she personally gets anxious when visiting the dentist and was aware that it causes her child to worry as well. Parents in the first study suggested that they tried to make sure their anxiety did not affect their children (Participants 5 and 9), although clearly the dentists in the second study considered that parental anxiety remained a problematic issue when providing treatment. This suggests that, despite awareness, parents may still be having a negative impact on their child's treatment.

Additional Anxieties

The first study demonstrated that many individuals with ASD also have additional anxieties that are not related to dental care. This conclusion is amply supported by the literature, which demonstrates that individuals with ASD are more prone to suffer from comorbid psychological disorders (De Bruin et al., 2007; Klin et al., 2005; MacNeil, et al., 2009; White et al., 2009). For example, Participant 3 spoke of phobias and panic attacks. Some dentists (Participants 1 and 3) were aware that individuals with ASD have other fears in addition to dental fear.

Sensory Sensitivity

The third theme of the first study covered sensory sensitivities, which were described in some detail by the ASD participants in the first study, in which it was split into seven sub-themes, relating to the different senses affected. For example, Participant 1 mentioned dislike of the bright light, Participants 6 and 7 spoke of the unique smells from the equipment and mouthwash, and Participant 8 mentioned vestibular symptoms, as patients are required to lie down in the dentist's chair. Such findings have been confirmed by the literature (DeMattei et al., 2007; Shapiro et al., 2009; Tomchek & Dunn, 2007).

While sensory sensitivity was mentioned by dentists in the second study as well, this topic was not covered to the same degree of depth by those participants. Sensory sensitivity in the second study was categorised under the second theme of the 'Causes of Dental Anxiety', although the responses demonstrate that some dentists are aware of individuals with ASD having a particular problem with this issue. For example, Participant 7 recognised that people with autism have '*a different sensory integration*'. Participant 1 suggested the high level of sensory sensitivity in individuals with ASD is problematic and Participant 4 spoke of the problems caused by light and sound.

Coping Strategies

The present study questioned participants from both groups about the strategies they use to cope with dental anxiety. This is a large and well-researched field and a number of strategies

have been tried and tested. In this respect, Participants 2 and 3 from the second study said that they tailored their approach to meet the needs of the ASD patient in particular. Indeed, the literature has suggested that dentists' responsiveness to patient needs is an important aspect of support (Mills, Frost, Cooper, Moles & Kay, 2014; Moosavi et al., 2015).

The findings from the first study generated several sub-themes: support from members of the family (Hall & Graff, 2011; Hastings & Johnson, 2001; Higgins et al., 2005) and schools; and measures taken by the participants themselves to make the process easier, such as preparing the child through regular practice (Participant 8), modelling and family visits. For example, Participant 6 said they would visit the dentist as a family and allow their child with ASD to watch as their relatives were treated first. Others mentioned steps they took to avoid dental caries in the first place (Participant 7).

Similarly, the dentists provided information as to how they approach dental anxiety in patients with ASD. Some referred to approaches, such as remaining calm and taking the anxiety seriously (Participant 1), and techniques, such as 'tell-show-do' and distraction (Participant 5), as well as providing sufficient information about the treatment (Participant 4). As mentioned, such techniques have been examined in the literature (Delli et al., 2013). It can be seen from comparing these studies that, while both sets of participants in either study were aware of coping strategies, they generally focused on different techniques. One overlap was that both Participant 5 from the second study and Participant 7 from the first both spoke of positive reinforcement, which can include things like rewards for good behaviour.

Other

Finally, in the first study, participants mentioned the effects of medication and also discussed some behavioural problems experienced, for example, poor attitudes towards siblings (Participant 5). While the dentists in the second study did not mention medication, they did comment on some of the behavioural problems they had experienced with the ASD population. Behavioural issues are of considerable concern to the present study and such problems have been found to be worse in the ASD than TD populations (Stein et al., 2014).

4.6 Conclusion

In general, the second qualitative study successfully identifies further factors that can cause dental anxiety and therefore meets the research aims. It is agreed that every study has its strengths and limitations, and the limitations of this thesis will be discussed in detail in Chapter 6. Nevertheless, one of the main limitations is the small sample size, which means it is relatively hard to draw more general conclusions concerning the wider population. Secondly, the interviews also rely on the dentists' own judgements and do not seek to elicit the factors that form the basis of their views. This is due to methodological issues, such as time constraints. However, it is not entirely clear what led the dentists to these conclusions, which is important since the reason why the dentists formed these beliefs could affect the accuracy of the results. For example, the dentist may have mistakenly concluded that a behaviour caused by ASD was the result of anxiety.

These qualitative studies has confirmed possible causes of dental anxiety mentioned by parents of children with ASD, individuals with ASD., and dentists This has allowed the researcher to study these causes further in the third study, which compares factors that affect dental anxiety in children with ASD and TD children, to be discussed in the next chapter.

5 Chapter Five

Dental Fear and Anxiety in Children with ASD compared to those with Typical Development: Quantitative Study

This study looks at factors that affect and predict the development of dental anxiety in individuals with ASD in comparison to TD children.

The first and second exploratory qualitative studies, Chapters Three and Four, were conducted with parents of individuals with ASD and individuals with ASD, as well as dentists. They suggest that there are a number of factors that affect the development of dental anxiety. These include parental anxiety, sensory sensitivities, cognitions and prior negative experiences. An overview of these factors is presented above in the literature review, as well as in the two Chapters Three and Four detailing the two exploratory studies. The results from the two qualitative studies suggested that sensory sensitives, parental anxiety, and previous negative experience are particularly important causes of dental anxiety for children and adults with ASD.

Fear of the unknown was mentioned frequently in the first qualitative study but was not discussed as much in the second qualitative study and while the variable was potentially of interest, it was felt necessary to limit the number of variables that were included in the present study. The primary reason for excluding fear of the unknown was to limit the sample size needed as regression analyses were planned and because fear of the unknown or unexpected events and difficulty with change and routine are well recognised in individuals with ASD and are measured in an indirect way in some of the questionnaires. Therefore, the researcher needed to prioritise the variables that are less well understood in relation to dental anxiety, such as cognitions and sensory processing and it was felt that the latter might be captured through a social anxiety subscale of an anxiety measure. Nevertheless, the researcher believes that it to be an important factor and would be interested in investigating it in the future.

In this chapter, factors are examined that are derived from current research and confirmed by parents of individuals with ASD, individuals with ASD themselves, and dentists

in a study comparing the role of these factors for children with ASD and typically developing children. Exploratory regression analysis is used to investigate and compare the factors that predict dental anxiety in these groups.

5.1 Aim of the Study

This study builds upon the two exploratory qualitative studies which focused on the possible causes of dental anxiety in ASD, which showed that children with ASD often have unusual fears about visiting the dentist and that dentists contribute to the levels of dental anxiety. Given the lack of previous literature investigating the factors associated with dental anxiety in ASD, the primary aim of this study was to explore these factors in a large sample of children with ASD.

5.2 Research Questions

The research questions were designed based on the results of the exploratory qualitative studies, which identified a number of significant issues for further investigation. These included other forms of anxiety, sensory processing, past negative experience, thoughts and worries about the dentist, as well as the impact of parental anxiety, and parental dental anxiety.

The research questions and hypotheses:

1. Do children with ASD experience dental anxiety more than TD children?

   It is hypothesised that reported dental anxiety will be higher in the ASD group than in the TD group.

2. Are fears about dental treatment and dental worries in children with ASD the same or different from TD children?

   This aim is exploratory and there are no specific hypotheses.

3 Is there a relationship between dental anxiety and other forms of anxiety?

   It is hypothesised that higher rates of anxiety are linked with higher rates of dental anxiety in both groups.

4 Is there a relationship between dental anxiety and sensory processing?

It is hypothesised that in ASD, unusual sensory profiles are associated with higher levels of dental anxiety. No such prediction is made for typically developing children, but an exploratory analysis was carried out.

5 Is there a relationship between negative cognitions and dental anxiety?

In typically developing children, it is hypothesised that negative cognitions will be associated with anxiety. In ASD, exploratory analyses were carried out because the role of cognition is not clear.

6 Is there an association between anxiety in parents and dental anxiety in children?

It is hypothesised that parental anxiety is associated with higher rates of dental anxiety in both groups.

7 Is there an association between dental anxiety in parents and dental anxiety in children?

It is hypothesised that parental dental anxiety is associated with higher rates of dental anxiety in both groups.

5.3 Method

5.3.1 Study Design

This cross-sectional study was conducted between October 2104 and May 2016 in the United Kingdom. In comparison to longitudinal studies that observe phenomena over a long period, cross-sectional studies focus on a representative proportion of the population at a single point in time (Sedgwick, 2014). Cross-sectional designs are often used to examine the prevalence of health issues (Sedgwick, 2014) and are well suited to methods that combine quantitative and qualitative approaches in order to draw conclusions about the group under examination (Zheng, 2015). The present study looked at TD children and children with ASD and drew comparisons between them in terms of their fears. In addition, the study investigated dental anxiety predictors in both groups.

5.3.2 Ethical Considerations

Ethical approval for the study was obtained from the University of Reading Research Ethics Committee (Appendix 28, p.281). Each parent/guardian was asked to read an information leaflet outlining the study and then sign a consent form. The consent form outlined the purpose of the study and its procedures, stated that participation was voluntary, and that they could withdraw from the study at any time. Parents signed the consent form for themselves and on behalf of their child, where appropriate (Appendix 17, p.256). The signed consent forms were then stored in a locked cabinet and participants were given a duplicate signed copy of this consent form to keep.

Each participant signed a consent form, which stated that they had been given a copy of the participant information sheet, had been given the opportunity to ask any questions and had been given a satisfactory answer. It also stated that the participant was aware that all personal information would remain confidential and any use of the information they provide will be anonymous. In addition, it stated that his/her participation was voluntary and that they could withdraw from the study at any time.

Dental anxiety and factors that affect its development which could be seen as a sensitive topic, especially for children who are afraid of the dental visits. A number of ethical issues were addressed regarding the participants, which were:

1- The participants were children, therefore, questionnaires were simplified when needed.
2- The sample of children with ASD could be considered vulnerable people. The researcher has taken this into consideration and therefore adaptations were made to some of the questions to address this matter.

Children with ASD, or individuals with ASD in general, are frequently asked to take part in research, which makes them lose interest in research. The researcher addressed this issue by providing a £20 Amazon voucher for the children who completed the research.

5.3.3 Study Power and Sample Size

The sample size was based on data from Stein et al.'s (2014) article entitled, '*Physiological and behavioural stress and anxiety in children with Autism Spectrum Disorders during routine oral care'*. This provided calculations of rates of dental fear in children and adolescents with ASD in comparison to TD children, using a wide variety of measures. A power calculation was carried out using G*power, based on the mean and standard deviation for typically developing children and children with ASD of the Anxiety and Cooperation Scale, and Children's Dental Behaviour Rating Scale. This indicated that a sample size of 18 for each group (ASD and TD) would be sufficient for between group comparisons.

However, a larger sample size was required for within-group analyses, such as multiple regression. Using a rule of thumb estimate of 10 participants per predictor, which were parental anxiety, sensory profile, cognitive appraisals, general anxiety, and previous negative experience, the present study required 50 children with ASD and a parent and 50 TD children and a parent. Consistent with the research questions detailed above, the following variables were identified in order to predict dental anxiety:

- General anxiety;
- Sensory profile;
- Cognitive appraisal;
- Previous negative experience.
- Parental anxiety;

5.3.4 Study Participants

The study used purposive and opportunistic sampling, which included children between the ages of 11 and 17 with ASD and their parents, as well as TD children in the same age range and their parents/caregivers. The inclusion criteria for children were as follows: that they were aged between 11 and 17 years, had a reading ability of age nine or above and, for children with ASD, had a recognised diagnosis of autism, ASD, Asperger's syndrome, atypical Autism and/or PDD-NOS. No direct test to ascertain reading ability was made; rather, this was estimated based

on the child's age, and information provided by their parents through the demographic questionnaire. Exclusion criteria included intellectual disability and non- English speaker. A description of the sample is summarised in Table 5.1.

Table 5.1: Description of sample

Group	***Children with ASD & a parent***			***TD children & a parent***	
Number of participants	45 children 45 parents			47 children 47 parents	
Age of child	13 years and 6 months			14 years and 6 months	
Ethnicity	38 UK	7 Arabs & others (0 Arabs & 7 others)		19 UK	28 Arabs & other (19 Arabs & 9 others)
Gender	32 males	13 females		21 males	26 females
School attended	36 mainstream	5 ASD resource	4 specialist school	All 47 children went to mainstream school	
Medical conditions	24 with medical conditions	21 with no medical conditions		9 with medical conditions	39 with no medical conditions
Medication	14 on medication	31 without medication		9 on medication	38 without medication

5.3.5 Recruitment

Recruitment of children with ASD was conducted through the Centre for Autism at the University of Reading. Adverts were sent to potential participants via newsletters, displayed on the website and also handed out during talks that were provided through the Centre for Autism.

Further recruitment was made through local voluntary sector organisations. Participants were located via advertising with the Berkshire Autistic Society (BAS) and other local groups, such as Parenting Special Children, West Berkshire Branch of National Autistic Society and similar organisations in Oxfordshire, Wokingham and Surrey. An advert for the study was also placed on the National Autistic Society website (NAS). TD children were recruited via the web using sites such as 'Netmums' and social media such as Facebook, as well as word of mouth.

The sample used in this study were from different backgrounds, ethnicities, age, and gender and that is because a large sample was needed in the current study. Therefore, several

sources were used to recruit the sample. However, because of this variation in the sample it is hard to generalise the outcomes. Moreover, the participants in this study are all diagnosed with Asperger's syndrome or HFA, which also limits the generalisation of the outcome.

The advertisements briefly described the study and the participants required and requested that interested participants email the researcher for further information (Appendix 18, p. 257). A standard flyer was adapted as required for the purposes of the organisations involved, although the basic text did not vary. The researcher's postal address and telephone contact details, in addition to the brief description of the study and participants were included in longer articles for newsletters or websites.

5.3.6 Study Instruments

The method chosen to investigate the research topic was self and parent-completion questionnaires. Questionnaires were considered appropriate since most of the questionnaires were standardised, which ensured the results could be compared with consistency. Questionnaires were also considered more effective in guiding the respondents, as well as less time-consuming than interviews considering the sample size. However, this of course meant that particular issues could not be explored in further depth in any given case.

5.4 Measures

5.4.1 Measures Completed by Child Participants:

Each child was given the following four questionnaires to complete:

1- Children's Fear Survey Schedule – Dental Subscale (CFSS-DS):

This measure was developed by Cuthbert and Melamed (1982) and is a standardised questionnaire that has been used widely and internationally (Kroniņa, Stradins & Care, 2014). The CFSS-DS has undergone various reliability and validity testing (Al-Namankany, De Souza, & Ashley, 2012) and has demonstrated high internal consistency, as well as good test-retest reliability, satisfactory criterion and construct validity in English, as well as numerous other languages (El-Housseiny et al., 2016). The research by Stein et al. (2014), mentioned above, is

the only recent study to have used the CFSS-DS with children with ASD, and those specifically within the age range of this present study.

The CFSS-DS contains 15 items with agreement with each statement rated on a 5 point Likert scale; items in this scale are related to dental situations and treatments. To ensure the items were understood and rated properly by the children (both ASD and TD), pictures of faces that represent each rating were added (Appendix 20, p. 263). Although the CFSS-DS shows good validity and reliability, it was found that parents tend to estimate the dental fear of their children slightly higher than their children's own scores show. Such findings have been confirmed by other research that has found mixed results in terms of parental assessments of anxiety (with some studies classifying this as 'good', while others as 'weak', or 'poor') (El-Housseiny, Merdad, Alamoudi & Farsi, 2015; Gustafsson, Arnrup, Broberg, Bodin & Berggren, 2010).

2- The Spence's Children's Anxiety Scale (SCAS: Spence, 1997)

This scale was developed to measure anxiety symptoms according to the DSM-IV anxiety disorders dimensions. The SCAS evaluates six aspects of anxiety: social phobia, separation anxiety, physical injury fears, generalised anxiety, panic/agoraphobia, and obsessive-compulsive disorder. Children were required to rate each experience on a 4-point frequency scale.

The scale involves 44 items in total; 38 of them are specific to anxiety symptoms and 6 are positive filler items to decrease negative response bias. The SCAS shows good psychometric properties, which makes it an acceptable measure for anxiety. Wigham and McConachie (2014) conducted a thorough assessment of psychometric measures, which were employed in intervention research for youngsters with ASD and anxiety. It was reported that the SCAS is a strong measure regarding its properties, and it showed high internal consistency (Wigham & McConachie, 2014; Zainal, Magiati, Tan, Sung, Fung, & Howlin, 2014). This scale has also been examined by other studies of tools used with children with ASD, including by Grondhuis and Aman (2012), who found the SCAS to be a measure commonly applied where

anxiety is comorbid with ASD. Those authors stated that the psychometric properties of the SCAS were 'fair-to-good', although commented that the scale lacks characteristics for children with ASD (Grondhuis & Aman, 2012).

The SCAS's broad applicability has led to it being relied upon extensively in studies for children, a recent example being May, Cornish, and Rinehart (2015). The SCAS's validity has led to it being used frequently as an outcome measure in studies of ASD and anxiety, as has been recognised in a meta-analysis undertaken by Sukhodolsky, Bloch, Panza, and Reichow (2013), as well as Kreslin, Robertson, and Melville's (2015) systematic review. Both drew on a number of studies that had used the SCAS. In addition, SCAS provides a version for the parent/caregiver to complete.

The SCAS's effectiveness has recently been examined by Zainal et al. (2014) in their paper, 'A Preliminary Investigation of the Spence Children's Anxiety Parent Scale as a Screening Tool for Anxiety in Young People with Autism Spectrum Disorders', which considered the utility of the SCAS-P (parental version) as an assessment measure for anxiety disorders. They found the SCAS-P apparently strikes an acceptable stability between level of sensitivity and specificity, apart from its positive predictive value, which the authors explained may be due to a lack of precision in appropriate screening for young people with clinically elevated levels of anxiety (Zainal et al., 2014).

3- Adolescent/Adult Sensory Profile (Brown & Dunn, 2002)

This self-questionnaire is intended to measure sensory processing and reflects neurological thresholds and self-regulation patterns (Blanche, Parham, Chang & Mallinson, 2014; Engel-Yeger, 2012). A person will respond to questions concerning how he /she reacts to sensations, in comparison to the way he/she he reacts at different time. The Adolescent/Adult Sensory Profile is divided into four quadrants based on an intersection between a neurological threshold continuum and a behavioural response continuum, namely, 1) low registration, 2) sensation seeking, 3) sensory sensitivity and 4) sensation avoiding (Brown & Stoffel, 2010).

Various studies have applied this measure in general research (Crane et al., 2009) and

the psychometric characteristics of this measure are good (Engel-Yeger, 2012). The Adolescent/Adult Sensory Profile has been considered the most widely used measure for adults with ASD (Tavassoli, Hoekstra & Baron-Cohen, 2014) and has been advised to be employed with children with ASD by professionals because of its accurate assessment of an individual's sensory processing threshold (Kern et al., 2007). The Adolescent/Adult Sensory Profile has been applied in several studies examining children with ASD (Hilton et al., 2010; Schoen, Miller, Brett-Green & Nielsen, 2009; Tomchek & Dunn, 2007), which makes it appropriate and useful for the current study.

4- The Dental Cognitions Questionnaire (DCQ) (De Jongh, Muris, Schoenmakers & Horst, 1995)

The DCQ has been found to demonstrate satisfactory psychometric characteristics, good internal consistency, high test-retest reliability, as well as satisfactory concurrent validity (Hood & Anthony, 2012). The DCQ uses a yes/no dichotomous scale consisting of 38 items that measure the individual's present beliefs about the dental care treatment. This scale is divided into two parts, of which the initial 14 questions examine beliefs about oneself and dentistry in general, and the subsequent 24 assess self-statements during treatment. This measure was modified after being piloted, with some of the items deleted and the language simplified, as required for the target sample, which resulted in a scale that is divided into three parts, of which the first seven questions examine worries about the dentist; the next three assess worries about the self and the last 19 examine worries about treatment.

Table 5.2: Changes in the Dental Cognitive Questionnaire

Original	Rephrased / Deleted Items		
Beliefs about Oneself and Dentistry in General	**Worries about the Dentists**		
When knowing that I have to undergo dental treatment very soon. I think:	This was removed and instead 'I think' was put before each statement.		
Dentists do as they please.	I think dentists do as they please	Yes	No
Dentists are often impatient.	I think dentists are often impatient.	Yes	No
The dentist does not care if it hurts.	I think dentists do not care if it hurts.	Yes	No
Dentists do not understand you.	I think dentists do not understand you.	Yes	No
Dentists are often incapable.	I think dentists are often not good at their job.	Yes	No
Dentists think you act childish.	I think dentists think I am acting childish.	Yes	No
Treatment often fail.	I think treatment won't work.	Yes	No
My teeth can't be saved.	Deleted	Yes	No
Worries about self			
I should be ashamed about my teeth.	I think I am ashamed of my teeth.	Yes	No
My teeth might break.	Deleted I did not find in the literature nor in my first study anything that mentioned fear about broken teeth.	Yes	No
I can't stand pain.	I think I can't stand pain.	Yes	No
I am a tense person.	I think I am a nervous person.	Yes	No
I am a difficult person.	Deleted They won't call themselves difficult, especially at this age.	Yes	No
I am someone with very long roots.	Deleted Very difficult questions for the age range.	Yes	No
Worries about Treatment			
While being treated, I think:			
Everything goes wrong.	I think everything will go wrong.	Yes	No
This treatment will hurt.	I think the treatment will hurt.	Yes	No
My teeth will break.	Deleted I did not find in the literature nor in my first study anything that mentioned fear about broken teeth.	Yes	No
Something surely will go wrong.	Deleted .	Yes	No
It never runs smoothly.	Deleted Similar to the 1st item in "worries about treatment".	Yes	No
I am helpless.	I think I can't tell the dentist when to stop.	Yes	No
I can't control myself.	I think I can't control myself.	Yes	No

I can't escape, I'm locked in.	I think I am locked in, I can't escape.	Yes	No
Anaesthetics often do not Work.	I think the injections won't numb my teeth.	Yes	No
The sound of the drill frightens me.	I think I will be scared of the sound of the drill.	Yes	No
The dentist will drill in my tongue, gums or cheek.	I think that the dentist will drill in my tongue , gums, or cheek.	Yes	No
The nerve will be touched.	Deleted For them it's pain in the teeth; they won't be able to tell if it's a nerve; too complicated.	Yes	No
I have no control over what happens.	I think I have no control over what happens.	Yes	No
I will die during treatment.	Deleted It is a risky question.	Yes	No
I will panic during treatment.	I think I will panic during. Treatment	Yes	No
I will faint during treatment.	I think I will faint during treatment.	Yes	No
I will suffocate during treatment.	I think I will have trouble breathing during treatment.	Yes	No
I can't stand this treatment for long.	I think I can't stand this treatment for long.	Yes	No
I will certainly have pain afterwards.	I think it will hurt after treatment.	Yes	No
The filling will certainly fall out and have to be made again.	I think that the filling will fall out and must be done again.	Yes	No
This treatment will fail.	Deleted Similar to the 7th item in "worries about the dentists".	Yes	No
I become sick.	I think I will become ill.	Yes	No
The dentist will lose control over his drill.	Deleted Similar to the 11th item in "worries about treatment".	Yes	No

5.4.2 Measures Completed by the Parents Regarding the Child

1- Dental Experiences Questionnaire (DEQ)

There are no standardised measures to record children's dental experiences and so information on this in published research often depends on dental records. The *Dental Experiences Questionnaire* was therefore constructed as a measure of frequency of typical dental experiences and adverse dental experiences. Some items were drawn from the Level of Exposure – Dental Experience Questionnaire (LOE-DEQ) (detailed by Oosterink, De Jongh,

Hoogstraten, & Aartman, 2008). The LOE-DEQ assesses an individual's previous experiences regarding negative dental experiences and is particularly suited to identifying psychological 'scars' that may have resulted directly from past treatment, or that may affect the administration of treatment in the future (Oosterink et al., 2008). The LOE-DEQ is considered to have good reliability, consistency, test–retest reliability and validity, although is recognised to detect dentally anxious subjects better than non-dentally anxious subjects (Oosterink et al., 2008).

The present study developed the Dental Experiences Questionnaire from the LOE-DEQ questionnaire and further items were added to the LOE-DEQ as a result of examining the literature. This is because there are no other standard measures available that assess negative experiences at the dentist. The study then applied the adapted LOE-DEQ to the individuals taking part in the study. Additional items were developed and added to this, based on the literature concerning factors that are important to child dental anxiety (Table 5.3).

Table 5.3: Dental Experiences Questionnaire

	OFTEN	SOMETIMES	NEVER
Please indicate any dental treatments and check-ups that your child has had**:**			
My child attends for check-ups.			
My child has his/her teeth cleaned by the dentist or hygienist.			
My child has had fluoride varnish or fissure sealants.			
My child has had a filling.			
My child has had an injection at the dentist.			
My child has had root canal treatment.			
My child has had a tooth extracted.			
My child has had a dental crown.			
My child has had orthodontic work (eg braces).			
Please indicate any unpleasant experiences that your child has had:			
My child has been criticized by a dentist.			
My child has been in a situation where a dentist did not seem to understand him/her.			
My child has been to a dentist who did not give him or her information about what was going to happen.			
My child had an impolite or rude dentist.			
Please indicate any painful experiences that your child has had			
My child had an injection by a dentist that caused a lot of pain.			
My child had a filling that hurt a lot.			
My child had root canal work that hurt a lot.			
My child suffered from extreme pain after a dental treatment.			
My child felt sick during dental treatment.			
My child almost suffocated during treatment.			
Please indicate any worrying things your child might have heard about or seen:			
My child has heard frightening stories about people's dental experiences.			
My child has heard information in the media about dental treatments that worried them.			
My child saw someone have painful dental work.			
My child saw someone who was very worried at the dentist.			

5.4.3 Measures Completed by All Parents

1- Hospital Anxiety and Depression Scale (HADS) (Zigmund & Snaith 1983)

The HADS is a 14-item self-assessment scale that has been found to be a reliable screening tool for detecting states of depression and anxiety. It is frequently used in clinical research and has good reliability and validity (Brennan, Worrall-Davies, McMillan, Gilbody & House, 2010; Hunt-Shanks, Blanchard, Reid, Fortier, & Cappelli 2010; Jutte, Needham, Pfoh, & Bienvenu, 2015).

2- Dental Anxiety Scale (DAS: Corah, 1969)

This is a scale used to measure dental anxiety in parents. The DAS has subsequently been modified and is now known as the Modified Dental Anxiety Scale and was developed to enhance the content validity along with the psychometrics of the initial DAS (Kim, Shim, Park, Kim & An, 2015). It has been found not to raise anxieties when being completed (Humphris & Hull, 2007). It has four items rated on a five point Likert scale. It asks participants to choose how relaxed or anxious they feel about four dentally related situations. Data collected has indicated that it is a reliable and valid scale and these values have been tested by various studies around the world (Bahammam & Hassan, 2014; Humphris et al., 2013; Kim et al., 2015).

5.4.4 Measures Completed by Parents of Children with ASD only

1- Social Communication Questionnaire (SCQ) (Rutter, Bailey, & Lord, 2003)

The SCQ is a measure that is designed for the primary caregivers of children with pervasive developmental disorders (Avcil, Baykara, Baydur, Münir, & Emiroğlu, 2015). A study that was conducted by Sappok, Brooks, Heinrich, McCarthy and Underwood (2016) verified the reliability and validity of the SCQ. Parents of children with ASD were given this questionnaire to complete, which offered a quick and reliable way to screen for ASD and to confirm the child's ASD diagnosis.

5.5 Piloting

As referred to previously, a pilot study was conducted with one child with ASD and the

parent, in which the measures were tested before being applied in the main study. This presented an opportunity to refine the measures for the present research and identify any weaknesses or complications that would need refining before being administered to the participant population.

During this stage, it was useful to test the applicability of the measures in terms of the research topic since very few measures have been designed specifically for children with ASD. It was therefore a good opportunity to see how the measures would work together to provide an overall view of dental fear in the context of ASD and any gaps in the information gathered could be accommodated through refinement of the measures where necessary. As mentioned, the CFSS-DS, DCQ and DEQ were modified in the main study following the pilot. In particular, the DCQ was piloted with a 14-year-old child with ASD and the questions she found difficult to understand were edited and simplified, while the DEQ was piloted with the parent.

5.6 Procedure

Participants who showed interest in taking part were sent a pack by post, which included participant information, consent form and questionnaires. In addition, a stamped addressed envelope was included for return postage. The participant information sheet explained the nature of the study. Three versions of this were available; one for parents of children with ASD (Appendix 14, p. 251), one for parents of TD children (Appendix 15, p. 253), and the last one for the children (Appendix 16, p. 255). An information leaflet given to the parents was designed to be used to inform them about the study and it helped them to talk about the study with their child. The participant information sheet for the children used simple language to explain the study and used pictures to make it more accessible. Parents were able to choose whether to show their children this information sheet, or the parent information sheet, which was more suitable for older children.

Participants were asked to complete a number of questionnaires, as described in the measures section above. Altogether, the questionnaires took about an hour to complete. Parents were encouraged to support their child as much as needed to complete the questionnaire. Children who took part in the study were given a £20 Amazon voucher.

5.7 Statistical analysis

To analyse demographic differences among the participants, differences in age, medication and medical conditions between TD and ASD were analysed by an independent sample t-test. Differences in ethnicity, gender and medication intake were analysed using a Chi-square test. Data were tested for normality using the Shapiro-Wilk test, and non-normally distributed data were analysed using non-parametric tests. Data were reported as means and standard deviations, and the accepted p value for significance was .05.

To compare TD children and children with ASD in the CFSS-DS score an independent sample t-test was used. The variables that did not meet assumptions for normality were analysed using non-parametric test to test differences between groups (Mann– Whitney U tests). These were SCAS, Sensory Profile, DCQ, DEQ, HADS and DAS.

An ANCOVA was completed to control for anxiety in general when comparing the levels of dental anxiety in both groups (ASD and TD) using the CFSS-DS. Spearman's Rho correlation was applied in all analyses except CFSS-DS, which was analysed using Pearson's correlation.

Using only gender and ethnicity from the demographics, which showed significance, tests were carried out controlling for these two variables using ANCOVA and partial correlation when comparing the two groups (ASD, TD) for sensory sensitivity, dental cognitions, dental experiences, parents' anxiety, and parents' dental anxiety. For non-parametric correlations, partial correlational were computed using the MATRIX OUT subcommand in NONPAR CORR (Nonparametric correlation) procedure to save a matrix of Spearman Rho correlations as the current data set. The partial correlation procedure can read this matrix as the input data by using the MATRIX IN subcommand, so that the partial correlations computed are based on Spearman rhos. The non-parametric correlation and partial correlation procedures must be run from a syntax window in order to use the /MATRIX subcommands. An example is given here:

```
* Encoding: UTF-8.
NONPAR CORR DEQDscore CFSSDSscore Gender Etnicity
/MISSING = LISTWISE
```

```
/MATRIX OUT(*).
RECODE rowtype_ ('RHO'='CORR') .
PARTIAL CORR DEQDscore CFSSDSscore BY Gender Etnicity
/MISSING = LISTWISE
/MATRIX IN(*).
```

To investigate the predictors of dental anxiety a linear regression was conducted using CFSS-DS as the dependent variable and the groups (ASD and TD) along with the other factors as independent variables. Moreover, an exploratory regression was undertaken by splitting the data according to development (ASD and TD) and using the factors that were shown to predict dental anxiety in the first regression.

5.8 Results

5.8.1 Demographics

AGE

The participants who took part varied in their age; the average for children with ASD was 164.76 months (*SD*= 24.85), i.e. 13 years and 6 months old. For TD children the average age was 176.94 months (*SD*=23.96), i.e. 14 years and 6 months.

The children with ASD were significantly younger than the typically developing group according to student's t-test (t (90) = 2.39, p=.02).

Correlations were carried out between age and all the measures to determine the effect of age on these measures. Table 5.4 demonstrate that age has no significant correlation with any of the measures except for physical injury (SCAS) in children with ASD.

Table 5.4: Correlations between age and all variables

Measure	Group	*R*	*P*
CFSS-DS	ASD	-.09	.55
	TD	-.10	.49
Social phobia	ASD	-.16	.31
	TD	-.05	.72
Panic/agoraphobia	ASD	-.12	.42
	TD	-.05	.73

Physical injury fears	ASD	-.34	.02*
	TD	.12	.48
Generalized anxiety	ASD	-.17	.28
	TD	.03	.83
Sensory Profile: low registration	ASD	-.11	.46
	TD	.14	.36
Sensory Profile: sensation seeking	ASD	.03	.82
	TD	-.10	.51
Sensory Profile: sensory sensitivity	ASD	-.19	.20
	TD	-.01	.95
Sensory Profile: sensation avoiding	ASD	-.23	.12
	TD	.06	.69
Worries about the dentist	ASD	-.06	.68
	TD	.01	.93
Worries about self	ASD	-.16	.30
	TD	-.03	.84
Worries about treatment	ASD	-.07	.66
	TD	.01	.97
Basic dental treatments	ASD	-.05	.73
	TD	-.09	.55
Advanced dental treatments	ASD	.19	.21
	TD	.01	.97
Unpleasant experiences	ASD	-.08	.63
	TD	-.01	.96
Painful experiences	ASD	-.02	.92
	TD	.04	.80

Worrying thing that the child might have heard or seen	ASD	-.27	.07
	TD	-.01	.94
HADS	ASD	.03	.86
	TD	.07	.67
DAS	ASD	-.13	.40
	TD	.05	.76

Ethnicity

The distribution of Arab, UK, and other participants varied between the groups. The TD group was composed of 19 Arab participants, 19 white UK participants and 9 others. The ASD group was composed of 38 white and 7 other. Chi square confirmed that the groups differed significantly in composition, X^2 (2) = 25.55, p <.001.

T-tests were carried out to determine the effect of ethnicity on all factors. Table 5.5 shows that ethnicity had a significant effect on several factors, which are highlighted below.

Table 5.5: T-test of Ethnicity and all other variables

Measure	Group	*t*	*P*
CFSS-DS	ASD	-3.50	.00
	TD	0.49	.63
Social phobia	ASD	-2.10	.08
	TD	-1.22	.23
Panic/agoraphobia	ASD	-1.80	.12
	TD	-0.81	.42
Physical injury fears	ASD	-2.34	.02
	TD	-2.01	.05
Generalized anxiety	ASD	-2.29	.03
	TD	-1.24	.22

Sensory Profile low registration	ASD	-2.18	.04
	TD	-2.05	.05
Sensory Profile sensation seeking	ASD	-2.50	.02
	TD	-2.52	.02
Sensory Profile sensory sensitivity	ASD	-3.34	.00
	TD	-2.02	.05
Sensory Profile Sensation avoiding	ASD	-2.01	.05
	TD	-2.58	.01
Worries about the dentist	ASD	-2.35	.02
	TD	0.34	.74
Worries about self	ASD	-0.59	.56
	TD	-0.51	.61
Worries about treatment	ASD	-4.26	.00
	TD	-0.10	.92
Basic dental treatments	ASD	0.49	.63
	TD	-0.02	.98
Advanced dental treatments	ASD	0.84	.41
	TD	-3.11	.00
Unpleasant experiences	ASD	-1.27	.21
	TD	-0.93	.36
Painful experiences	ASD	-0.13	.90
	TD	-3.04	.01
Worrying thing that the child might have heard or seen	ASD	-1.16	.29
	TD	-3.11	.00
HADS	ASD	0.34	.74

	TD	-1.07	.29
DAS	ASD	-1.92	.06
	TD	0.65	.52

Gender

The proportion of boys and girls was significantly different in TD and ASD groups (X^2 (2) = 6.58, p=.01, Chi-square test). In particular, the ASD group had a higher proportion of boys (32 boys and 13 girls).

T-tests were carried out to determine the effect of gender on all factors. Table 5.6 shows that gender had a significant effect on several factors, which are highlighted below.

Table 5.6: T-test Gender and other variables

Measure	**Group**	***t***	***P***
CFSS-DS	ASD	2.05	.05
	TD	-1.71	.09
Social phobia	ASD	-4.86	<.001
	TD	-2.88	.01
Panic/agoraphobia	ASD	-4.94	<.001
	TD	-1.67	.10
Physical injury fears	ASD	-1.72	.09
	TD	-2.06	.05
Generalized anxiety	ASD	-3.05	.00
	TD	-2.66	.01
Sensory Profile: low registration	ASD	-1.47	.15
	TD	.33	.74
Sensory Profile: sensation seeking	ASD	-1.13	.27
	TD	-.54	.59
	ASD	-4.80	<.001

Sensory Profile: sensory sensitivity	TD	-1.38	.18
Sensory Profile: sensation avoiding	ASD	-4.59	<.001
	TD	-1.03	.31
Worries about the dentist	ASD	-2.05	.01
	TD	-.03	.98
Worries about self	ASD	-2.23	.03
	TD	-1,87	.07
Worries about treatment	ASD	-2.58	.02
	TD	-1.96	.06
Basic dental treatments	ASD	.04	.97
	TD	-1.31	.20
Advanced dental treatments	ASD	2.31	.03
	TD	.01	.99
Unpleasant experiences	ASD	-.39	.70
	TD	.14	.89
Painful experiences	ASD	.20	.84
	TD	.22	.83
Worrying thing that the child might have heard or seen	ASD	-1.09	.28
	TD	1.01	.32
HADS	ASD	.04	.97
	TD	-.39	.70
DAS	ASD	-.99	.33
	TD	.88	.39

Medical conditions and medications

Some of the participants who took part had medical conditions and were on medications. Children with ASD had more cases of comorbid conditions than TD children (X^2 (2) = 11.68, p=.001, Chi-square test). However, there was no significant difference between TD and ASD in medication intake.

5.8.2 Tests for Normality

1- Children Fear Survey Schedule- Dental Subscale (CFSS-DS)

Table 5.7: Normality test for the CFSS-DS

	Shapiro-Wilk					
	Children with ASD			TD children		
	stat	*df*	sig	stat	*df*	sig
CFSS-DS	.954	45	.07	.969	47	.24

Shapiro-Wilk test for Children Fear Survey Schedule- Dental subscale (CFSS-DS) showed that CFSS-DS was normally distributed in both the ASD and typically developing groups.

2- Spence Children's Anxiety Scale (SCAS)

Table 5.8: Normality test for the SCAS

	Shapiro-Wilk									
	Children with ASD					TD children				
	Stat	df	Sig	skewness	kurtosis	stat	df	sig	Skew	kurtosis
Total score	.89	45	.001**	1.29	2.06	.97	47	.30	.50	.03
Separation anxiety	.91	45	.001**	1.16	1.70	.91	47	.001**	1.09	1.39
Social phobia	.91	45	.001**	2.10	4.72	.97	47	.24	-.73	7.29
Obsessive compulsive	.97	45	.20	.36	-.36	.96	47	.14	.32	-.65
Panic/ agoraphobia	.90	45	.001**	1.05	.88	.82	47	<.001**	1.57	2.59
Physical injury fears	.94	45	.02*	.79	.17	.90	47	.001**	.87	.20
Generalized anxiety	.95	45	.04*	.65	-.13	.97	47	.17	.39	-.54

Table 5.8 shows that neither the total SCAS nor any of its subscales of the SCAS relating to children with ASD were normally distributed, except for the obsessive compulsive subscale. The TD children's total score was normally distributed, as were social phobia, obsessive compulsive, and generalized anxiety. However, panic/agoraphobia, separation anxiety, and physical injury fears sub-scales were non-normal.

3- Adolescent/Adult Sensory Profile (SP)

Table 5.9: Normality test for the SP

	Shapiro-Wilk									
	Children with ASD					TD children				
	Stat	df	Sig	Skewness	Kurtosis	stat	df	sig	Skewness	Kurtosis
Low registration	.971	45	.32	.21	-.58	.949	47	.04*	.88	1.03
Sensation seeking	.887	45	.001**	1.47	5.84	.986	47	.84	-.25	-.03
Sensory sensitivity	.954	45	.07	.40	-.80	.983	47	.74	.26	-.46
Sensation avoiding	.986	45	.85	.02	-.66	.980	47	.60	.34	.04

Table 5.9 shows that the sensory processing subscales of children with ASD were normally distributed, except for sensation avoiding. TD children's sub-scales were also normally distributed, except for low registration.

4- Dental Cognitive Questionnaire (DCQ)

Table 5.10: Normality test for the DCQ

	Shapiro-Wilk									
	Children with ASD					TD children				
	stat	df	Sig	Skewness	Kurtosis	stat	df	sig	Skewness	Kurtosis
Worries about the dentist (A)	.875	45	.001**	.54	-.81	.825	47	<.001**	1.15	.46
Worries about self (B)	.878	45	.001**	.03	-.85	.799	47	<.001**	.47	.-1.32
Worries about the treatment (C)	.939	45	.02*	.51	-.58	.930	47	.01**	.53	-.57

Shapiro-Wilk test for DCQ showed that none of the subscales (DCQA, DCQB, DCQC) of the DCQ was normally distributed for either ASD or typically developing groups.

5- Dental Experiences Questionnaire (DEQ)

Table 5.11: Normality test for the DEQ

	Shapiro-Wilk									
	Children with ASD					TD children				
	Stat	df	sig	Skewness	Kurtosis	stat	df	sig	Skewness	Kurtosis
Basic Treatment (DEQA_1)	.933	45	.01*	.10	-.50	.936	47	.01*	.06	-.52
Advanced treatments (DEQA_2)	.811	45	.001**	1.18	.79	.908	47	.001**	.70	-.04
Unpleasant experiences (DEQB)	.832	45	.001**	1.43	2.07	.707	47	<.001**	2.14	6.29
Painful experiences (DEQC)	.666	45	.001**	1.49	1.21	.623	47	<.001**	1.71	1.70
Worrying things the child might have heard or Seen (DEQD)	.666	45	.001**	1.76	2.55	.719	47	<.001**	1.84	3.57

Shapiro-Wilk test for DEQ showed that the none of the subscales (DEQA_1, DEQA_ 2, DEQB, DEQC,DEQD) of the DEQ was normally distributed, in either the autism or typically developing groups.

6- Hospital Anxiety and Depression Scale (HADS)

Table 5.12: Normality test for the HADS

	Shapiro-Wilk									
	Parents of Children with ASD					TD children				
	Stat	Df	Sig	Skewness	Kurtosis	stat	df	sig	Skewness	Kurtosis
Hospital anxiety scale	.976	45	.46	-.14	-.09	.936	47	.01*	.38	.08

Table 5.12 shows that the HADS anxiety scale for parents of children with ASD was normally distributed. Parents of TD children HADS anxiety scale was non-normally distributed.

7- Norman Corah's Dental Questionnaire (DAS)

Table 5.13: Normality test for the DAS

	Shapiro-Wilk									
	Children with ASD					TD children				
	Stat	df	sig	Skewness	Kurtosis	stat	df	sig	Skewness	Kurtosis
Norman Corah's Dental Questionnaire	.933	45	.01*	.68	-.25	.937	47	.01*	.82	.39

Shapiro-Wilk test for Norman Corah's Dental Questionnaire (DAS) showed that the DAS was non-normally distributed for both the ASD and typically developing groups.

5.8.3 Comparison between ASD and TD Children and Hypothesis Testing

Table 5.14: Mean and Standard Deviation on all measures

Variable Name	ASD Mean (SD)	TD Mean (SD)
Children's Fear Survey Schedule – Dental Subscale	39.78 (14.43)*	34.17 (11.83)
Spence Children's Anxiety Scale		
Total	37.87 (17.20)	31.28 (17.58)
Generalized Anxiety	7.91 (3.31)	7.53 (4.13)
Panic/Agoraphobia	6.13 (4.72)*	4.15 (4.68)
Social Phobia	7.29 (3.52)	6.96 (3.96)
Separation Anxiety	5.29 (3.96)*	3.68 (2.96)
OCD	6.24 (2.82)*	4.72 (3.10)
Physical Injury	5.00 (3.32)	4.34 (3.12)
Dental Cognitive Questionnaire		
Worries about the Dentist	2.29 (2.20)	1.53 (1.64)
Worries about Self	1.38 (0.94)	1.11 (1.17)
Worries about Treatment	7.40 (5.59)*	5.55 (4.57)
Sensory Profile		
Slow Registration	40.60 (9.58)*	33.64 (10.09)
Sensory Seeking	39.47 (8.48)*	45.26 (8.83)
Sensory Sensitivity	42.71 (10.39)*	38.21 (10.63)
Sensory Avoiding	43.58 (10.15)*	35.59 (11.03)
Dental Experiences Questionnaire		
Basic Treatments that child has had	3.24 (1.42)	3.53 (1.39)
Advanced Treatments that child has had	1.31 (1.55)*	2.43 (2.05)

Unpleasant Experiences that child has had	1.69 (1.69)*	0.83 (1.20)
Painful Experiences that child has had	0.67 (1.09)	0.85 (1.50)
Worrying Things that child might have heard or seen	0.71 (1.14)	1.19 (1.74)
Hospital Anxiety Scale	8.11 (3.35)	7.91 (3.17)
Norman Corah's Dental Questionnaire	10.29 (3.74)	9.21 (3.18)

* ASD is significantly different from TD (p <0.05)

These comparisons were carried out to explore differences between children with ASD and typically developing children.

When controlling for ethnicity and gender, the adjusted means for both groups (ASD and TD) on all the measures are presented in table 5.15 below:

Table 5.15: Adjusted Means on all measures

Variable name	Adjusted ASD Mean	Adjusted TD Mean
Children's Fear Survey Schedule – Dental subscale	42.84	33.36
Spence Children's Anxiety Scale		
Total	44.74	29.55
Generalized Anxiety	9.06	7.23
Panic/Agoraphobia	7.62	3.76
Social Phobia	8.70	6.58
Separation Anxiety	6.40	3.38
OCD	6.93	4.54
Physical Injury	6.03	4.06
Dental Cognitive Questionnaire		
Worries about the Dentist	2.59	1.45
Worries about Self	1.55	1.06
Worries about Treatment	8.97	5.14
Sensory Profile		
Slow Registration	43.03	32.97
Sensory Seeking	42.08	44.54
Sensory Sensitivity	46.83	37.11
Sensory Avoiding	47.41	34.57
Dental Experiences Questionnaire		
Basic Treatments that Child Have Had	3.26	3.53
Advanced Treatments that Child Have Had	1.52	2.36
Unpleasant experiences that Child Have Had	1.87	.78

Painful Experiences that Child Have Had	.79	.89
Worrying Things that Child Might Have Heard or Seen	1.06	1.09
Hospital Anxiety Scale	8.30	7.86
Norman Corah's Dental Questionnaire	10.49	9.16

Children's Fear Schedule Survey

Children's Fear Survey Schedule – Dental subscale is used to measure dental anxiety. Using an independent samples t-test, children with ASD had a significantly greater level of dental anxiety as opposed to the TD group (t (90) = -2.04, $p < 0.05$).

A one-way ANCOVA was conducted to examine the rates of dental anxiety in both groups (AD and TD) when overall anxiety is controlled (Totalscas). There was a significant effect of overall anxiety on CFSS-DS (F (1, 89) = 39.30, p<.001, partial eta squared = .31). There was no statistically significant effect of group on CFSS-DS (F (1, 89) =1.53, p = .22, partial eta squared = 0.017) after controlling for anxiety score, which means that children with ASD have similar levels of dental fear as TD children when overall anxiety is controlled.

To control for gender and ethnicity, a one- way ANCOVA was conducted to examine the rates of dental anxiety in both groups (ASD and TD) when gender and ethnicity were controlled. There was a significant effect of gender on CFSS-DS (F (1, 92) = 7.36, p=.01). The effect of ethnicity of on CFSS-DS showed a trend (F (1, 92) = 2.95, p=.09). After controlling for gender and ethnicity children with ASD had higher dental anxiety means *(adjusted* M=42.79) than TD children (adjusted M=33.07).

Are fears about dental treatment and dental worries in children with ASD the same or different from TD children?

An independent t-test was performed on all 15 items of the Children's Fear Schedule Survey - Dental sub-scale (see Table 5.16 next page) to investigate whether children with ASD worry about or fear the same things as TD children. A Holm–Bonferroni correction was carried out to control the high probability of type 1 error (false positive), which is more likely to occur when testing for several items and hypotheses (in this case 15 items of the CFSS-DS).

The Holm–Bonferroni is a method used in statistics for multiple comparisons and to rule out any significant results that occur by chance. It provides a more powerful result than a Bonferroni correction by controlling the family-wise error (Holm, 1979). The Bonferroni correction multiplies each probability by the total number of tests performed while, in the Holm-Bonferroni, tests need first to be performed in order to obtain their "p-values." The tests are then ordered from the one with the smallest p-value to the one with the largest p-value. The test with the lowest probability is tested first with a Bonferroni correction involving all tests. A Bonferroni correction requires finding the critical value (alpha) for an individual test by dividing the familywise error rate (usually 0.05) by the number of tests. Thus if you are doing 100 statistical tests, the critical value for an individual test would be 0.05/100=0.0005, and you would only consider individual tests with p <0.0005 to be significant (McDonald, 2014). The second test is tested with a Bonferroni correction involving one less test and so on for the remaining tests. Holm's approach is more powerful than the Bonferroni approach but it still keeps under control the inflation of the Type 1 error (Holm, 1979).

Table 5.16: T-test of the 15 CFSS-DS subscale items

Item	**ADS mean (SD)**	**TD Mean (SD)**	***T* Value**	***P* Value**	**Holm Bonferroni Correction**
Injections	3.29 (1.42)	2.98 (1.43)	1.04	.30	1.00
Choking	3 (1.33)	3.17 (1.39)	.60	.55	1.00
The dentist drilling	3.27 (1.53)	2.23 (1.31)	1.69	.09	1.00
The noise of the dentist drilling	3.11 (1.40)	2.66 (1.48)	1.50	.14	1.00
The sight of the dentist drilling	2.91 (1.43)	2.68 (1.37)	.79	.43	1.00
Having a stranger touch you	2.84 (1.30)	2.43 (1.26)	1.57	.12	1.00
Having to go to the hospital	2.84 (1.36)	2.43 (1.21)	1.56	.12	1.00
Having someone put instruments in your mouth	2.87 (1.38)	2.38 (1.07)	1.87	.06	.77
Having somebody examine the mouth	2.64 (1.79)*	1.79 (.86)	3.72	.01	.01*

Dentists	2.38 (1.21)	2.02 (1.03)	1.52	.13	1.00
Having somebody look at you	2.24 (1.32)	2.15 (1.20)	.36	.72	1.00
Doctors	2.24 (1.09)	2.06 (1.03)	.82	.42	1.00
Having a nurse clean your teeth	2.29 (1.44)	1.77 (1.16)	1.91	.06	.75
Having to open your mouth	2.07 (1.27)	1.47 (.78)	2.72	.01	.11
People in white uniforms	1.78 (1.26)	1.43 (.93)	1.52	.13	1.00

These analyses show that, after correction, there were few differences between individuals with ASD and TD children in the CFSS-DS items, meaning that the degree of anxiety reported is very similar across the aspects of treatment captured by the CFSS-DS. However, children with ASD reported significantly higher anxiety about someone examining the mouth than typically developing children.

Spence Children Anxiety Scale

The Spence Children's Anxiety Scale is used to measure level of anxiety (Separation anxiety, social phobia, obsessive-compulsive disorders, panic/agoraphobia, physical injury fears, generalised anxiety).

Differences in anxiety subscales among ASD and TD children were compared using a Mann-Whitney U test. The Mann-Whitney U test indicated that the separation anxiety was significantly greater for children with ASD than for TD children (Median=4, U=788, p=.03). It also indicated that obsessive-compulsive disorder was greater in children with ASD than TD children (Median=5.5, U=761, p=.02), as was As well as panic/agoraphobia that was higher in children with ASD than TD Children (Median=3.00, U=728, p=.01). However, there was no differences between the groups in social phobia, physical injury or generalized anxiety.

It was hypothesised that higher rates of anxiety would be associated with higher rates of dental anxiety in both groups

Spearman's Rho correlation was conducted for children with ASD and TD children separately to examine the relationship between some of the Spence Children Anxiety Scale (SCAS) subscales and the Children's Fear Survey Dental sub-scale (CFSS-DS). The variables included from the SCAS were: social phobia, panic/agoraphobia, physical injury fears, and generalized anxiety. The subscales that were chosen from the Spence Children's Anxiety Scale (SCAS) to be tested were the ones that have been highlighted in the literature to have an effect on dental anxiety. Therefore, separation anxiety and obsessive compulsive disorders were not included as there is no record of them effecting dental anxiety (Table 5.17).

Table 5.17: Spearman's Rho Correlation between SCAS and CFSS-DS

Item	**Groups**	***Spearman's Rho Correlation***		**Fisher r-to-z transformation**	
		R	*P*	*z*	*p*
Social Phobia	ASD	.28	.06	-.1	.92
	TD	.30	.02*		
Panic/Agoraphobia	ASD	.50	.001**	1.56	.12
	TD	.21	.15		
Physical Injury Fears	ASD	.66	.001**	1.66	.10
	TD	.41	.004**		
Generalized Anxiety	ASD	.51	.001**	.81	.42
	TD	.37	.01*		

Table 5.17 shows that, in children with ASD, there was a strong correlation between dental anxiety and panic/agoraphobia (r=.50), physical injury fears (r=.66), and generalized anxiety (r=.53). This shows that having higher levels of dental anxiety is associated with higher levels of these other anxiety types.

TD children had a significant correlation between dental anxiety and social phobia (r=.30), physical injury fears (r=.41), and generalized anxiety (r=.29), which also means that having dental anxiety is related to having one or more of these anxieties or one of them. The

strength of each correlation for the ASD group was compared to the correlation for the TD group using Fisher r-to-z transformation, which showed no difference between the two groups.

Taking into account that gender and ethnicity have a significant effect on some of the variables, mentioned previously in the demographics (5.8.1), partial correlations were carried out to demonstrate the relationship between dental anxiety (CFSS-DS) and SCAS when controlling for ethnicity and gender.

Table 5.18: Relationship between SCAS and CFSS-DS when ethnicity and gender are controlled

Controlled variables	**Item**	**Groups**	***Partial Spearman's Rho Correlation***	
			R	*P*
Gender and Ethnicity	**Social phobia**	ASD	.08	.62
		TD	.28	.06
	Panic/agoraphobia	ASD	.40	.01*
		TD	.15	.32
	Physical injury fears	ASD	.62	<.001**
		TD	.40	.01*
	Generalized anxiety	ASD	.40	.01*
		TD	.32	.03*

Table 5.18 shows that in children with ASD demonstrated similar relationships between SCAS and dental anxiety with c and without controlling variables (ethnicity and gender). The partial correlations show that there was a strong correlation between dental anxiety and panic/agoraphobia (r=.40, p=.01), physical injury fears (r=.62, p<001), and generalized anxiety (r=.40, p=.01). This shows that having higher levels of dental anxiety is associated with higher levels of these other anxiety types.

TD children had a significant correlation between dental anxiety and physical injury fears (r=.40), and generalized anxiety (r =.32), which also means that having dental anxiety is related to having one or both of these anxieties. The TD children's results differed when ethnicity and gender were controlled for social phobia, as significant correlation occurred

before these variables were controlled, and after the partial correlation the association between social phobia and dental anxiety diminished.

Sensory Profile

The sensory profile is used to identify sensory processing patterns. Differences between children with ASD and TD children in the sensory profile were compared using Mann-Whitney U test. It was demonstrated that low registration was significantly greater for children with ASD than for TD children (Median=35.5, *U*=612.50, *p*=.001). Low registration refers to a pattern of sensory processing which can be described by great sensory thresholds as well as passive self-regulation approach (Dunn, 1997); when individuals have a low registration pattern of sensory processing, they notice sensory stimuli much less than others. It also shows that sensation avoiding was greater in children with ASD than TD children (Median=38.5, *U=615.50, p*=.001). Sensation seeking was different between the two groups (Median=43, *U*=615, *p* =.001), which was higher in TD children, A trend was also seen in sensory sensitivity (*U*=818, *p*=.06.).

It was hypothesised that, in ASD, unusual sensory profiles would be associated with higher levels of dental anxiety. No such prediction was made for typically developing children but an exploratory analysis was carried out.

Spearman's Rho correlation was conducted between sub-scales of the Sensory Profile and Children's Fear Survey Schedule- Dental Sub-scale (CFSSS-DS).

Table 5.19: Spearman's Rho Correlation between Sensory Profile and CFSS-DS

Item	**Groups**	**Spearman's Rho correlation**		**Fisher r-to-z transformation**	
		R	*p*	*z*	*p*
Sensory Profile: low registration	ASD	.50	<.001**	2.13	.03*
	TD	.09	.56		
Sensory Profile: sensation seeking	ASD	.17	.28	-.19	.85
	TD	.21	.17		
	ASD	.62	<.001**	1.29	.20

Sensory Profile: sensory sensitivity	TD	.42	.004**		
Sensory Profile: sensation avoiding	ASD	.54	<.001**	1.52	.13
	TD	.27	.06		

Table 5.19 shows that the children with ASD demonstrated a strong correlation between dental anxiety and low registration (*r*=.50), sensory sensitivity (*r*=.62), and sensation avoiding (*r*=.54). This shows that having higher levels of dental anxiety is associated with unusual processing of sensory stimuli. The TD children showed a significant correlation between dental anxiety and sensory sensitivity (*r*=.42), which implies that having higher levels of dental anxiety is associated with higher levels of these sensory sensitivities. The strength of each correlation for the ASD group was compared to the correlation for the TD group using Fisher r-to-z transformation, which showed no difference between the two groups except for the low registration, which means that children with ASD and TD children differ in the way they notice and process sensory stimuli.

Taking into account that gender and ethnicity have a significant effect on some of the variables, as mentioned previously in the demographics section (5.8.1), partial correlations were carried out to demonstrate the relationship between dental anxiety (CFSS-DS) and sensory profile when controlling for ethnicity and gender.

Table 5.20: Relationship between SP and CFSS-DS when ethnicity and gender are controlled

Controlled variables	**Item**	**Groups**	***Partial Spearman's Rho Correlation***	
			R	*P*
Gender and Ethnicity	**SPlowregistartion**	ASD	.42	.01*
		TD	.14	.35
	SPsensationseeking	ASD	.09	.62
		TD	.22	.15
	SPsensorysensitivity	ASD	.51	<.001**
		TD	.42	.004*
	SPsensationavoiding	ASD	1.00	<.001**
		TD	.95	.20

Table 5.20 shows that in children with ASD demonstrated similar relationships between sensory profile and dental anxiety with the controlling variables (ethnicity and gender) and without. The partial correlations show that there was a strong correlation between dental anxiety and low registration (r=.42, p=.01), sensory sensitivity (r=.51, p=<.001), and sensation avoiding (r= 1.00, p=<.001). This shows that having higher levels of dental anxiety is associated with higher levels of these other anxiety types.

The TD children had a significant correlation between dental anxiety and sensory sensitivity (r=.42, p=.004), which was also the case when correlation was carried out without controlling for ethnicity and gender.

Dental Cognitive Questionnaire

A Dental Cognitive Questionnaire is used to measure negative cognitions related to dental care treatment. Differences in Dental Cognitive sub-questionnaires between individuals with ASD and typically developing children were compared using Mann-Whitney U. There were no significant differences between the two groups in their worries about the dentist, about self worries and worries about treatment.

It was hypothesized that, in typically developing children negative cognitions would be associated with anxiety. In children with ASD, exploratory analyses were carried out because the role of cognition is not clear.

A Spearman's correlation analysis was carried out between the Dental Cognitive Questionnaire (DCQ) and the Children's Fear Survey Schedule - Dental subscale (CFSS-DS).

Table 5.21: Spearman's Rho correlation between DCQ and CFSS-DS

Item	Group	Spearman's Correlation		Fisher r-to-z Transformation	
		R	*P*	*Z*	*p*
Worries about the dentist	ASD	.46	.002**	-.18	.86
	TD	.49	.001**		
Worries about self	ASD	.34	.02*	-.72	.47
	TD	.47	.001**		
Worries about treatment	ASD	.78	.001**	1.84	.07
	TD	.57	.001**		

Table 5.21 shows that children with ASD had a strong correlation between dental anxiety and worries about treatment (r=.78), and worries about the dentist (r=.46). Nevertheless, there was a moderate correlation between dental anxiety and worries about self (r=.34). This shows that higher levels of dental anxiety are associated with these worries.TD children had a significant correlation between dental anxiety and worries about treatment (r=.57), worries about dentist (r=.49), and worries about self (r=.47), which implies that having higher levels of dental anxiety is associated with these worries.

The strength of each correlation for the ASD group was compared to the correlation for the TD group using Fisher r-to-z transformation, which showed no difference between the two groups but there was a strong trend in the worries about treatment.

Taking into account that gender and ethnicity have a significant effect on some of the variables, which are mentioned previously in the demographics section (5.8.1), partial correlations were carried out to demonstrate the relationship between dental anxiety (CFSS-DS) and DCQ when controlling for ethnicity and gender.

Table 5.22: Relationship between DCQ and CFSS-DS when ethnicity and gender are controlled

Controlled variables	Item	Group	*Partial Spearman's Rho Correlation*	
			R	*P*
Gender and Ethnicity	**Worries about the dentist**	ASD	.36	.02*
		TD	.49	.001**
	Worries about self	ASD	.26	.06
		TD	.44	.003**
	Worries about treatment	ASD	.71	<.001**
		TD	.55	<.001**

Table 5.22 shows that children with ASD demonstrated almost the same relationship between cognitions and dental anxiety with controlling variables (ethnicity and gender) and without. The partial correlations in children with ASD show that there was a strong correlation between dental anxiety and worries about the dentist (r=.36, p=.02) and worries about treatment (r=.71, p= <.001), the only difference was that children with ASD demonstrated a significant correlation between dental anxiety and worries about self when ethnicity and gender were not controlled.

TD children had a significant correlation between dental anxiety and worries about the dentist (r=.49, p=001), worries about self (r=.44, p=.003), and worries about treatment (r=.55, p=<.001), which was also the case when correlations were carried out without controlling for ethnicity and gender.

Dental Experience Questionnaire

The Dental Experience Questionnaire is used to measure previous experiences of dental visits. Differences between children with ASD and TD children in the Dental Experience Questionnaire were compared using Mann-Whitney U. Children with ASD reported greater numbers of unpleasant experiences than TD children (Median=1.00, U=693.50, p=.003). Nevertheless, it was shown that TD children had greater numbers of advanced treatments than children with ASD (Median=1.5, U=715, p=.01). There were no differences between the two

groups in their receipt of basic treatment such as check-ups and cleaning, painful experiences, and the worries they had from things that they had heard or seen.

It is hypothesised that negative experiences would be associated with anxiety in both groups.

A Spearman's correlation analysis was conducted between the Dental Experience Questionnaire and the Children's Fear Survey Schedule-Dental Subscale (CFSS-DS)

Table 5.23: Spearman's Correlation between Dental Experience Questionnaire and CFSS-DS

Item	Group	Spearman's Correlation		Fisher r-to-z transformation	
		R	*P*	*Z*	*P*
Basic dental treatments	ASD	-.32	.03*	-1.21	.23
	TD	-.07	.64		
Advanced dental treatments	ASD	-.29	.05	-1.4	.16
	TD	.003	.98		
Unpleasant experiences	ASD	.13	.40	-1.3	.19
	TD	.39	.01**		
Painful experiences	ASD	-.03	.82	-1.68	.09
	TD	.32	.03*		
Worrying things that the child might have heard or seen	ASD	.07	.67	-1.69	.09
	TD	.41	.004**		

Table 5.23 shows that children with ASD had a negative correlation between dental anxiety and receiving basic dental treatments (r=-.32). This shows that receiving more dental treatment is associated with lower levels of dental anxiety. Moreover, there is a strong association between dental anxiety and not receiving advanced dental treatments (r=-.29, p=.05).

TD children had a significant correlation between dental anxiety and unpleasant experiences (r=.39), painful experiences (r=.32), and worrying things that the child might heard have or seen (r=.41), showing that having higher levels of dental anxiety is associated with higher levels of these experiences.

The strength of each correlations for the ASD group was compared to the correlation for the TD group using Fisher r-to-z transformation, which showed no differences between the

two groups. Nevertheless, the association with painful experiences and the worrying things that the child might have heard or seen was stronger in TD children.

Taking into account that gender and ethnicity have a significant effect on some of the variables, as mentioned previously in the demographics section (5.8.1), partial correlations were carried out to demonstrate the relationship between dental anxiety (CFSS-DS) and DEQ when controlling for ethnicity and gender.

Table 5.24: Relationship between DEQ and CFSS-DS when ethnicity and gender are controlled

Controlled Variables	**Item**	**Group**	***Partial Spearman's Rho Correlation***	
			R	*P*
Gender and Ethnicity	**Basic dental treatments**	ASD	-.32	.04*
		TD	-.11	.46
	Advanced dental treatments	ASD	.23	.14
		TD	.02	.89
	Unpleasant experiences	ASD	.06	.72
		TD	.40	.01*
	Painful experiences	ASD	-.54	.73
		TD	.37	.01*
	Worrying thing that the child might have heard or seen	ASD	-.003	.98
		TD	.49	.001**

Tale 5.24 shows that children with ASD demonstrated similar relationship between cognitions and dental anxiety with controlling variables (ethnicity and gender) and without. The partial correlations in children with ASD show that there was a strong negative correlation between dental anxiety and receiving basic treatments (r=-.32, p=.04).

TD children had a significant correlation between dental anxiety and unpleasant experience (r=.40, p= .01), painful experience (r=.37, p=.01), and worrying things that the child might have heard or seen (r=.49, p =.001), which was also the case when correlations were carried out without controlling for ethnicity and gender.

Hospital Anxiety and Depression Scale

This questionnaire is used to measure parental anxiety. A Mann-Whitney U was performed to compare parents of children with ASD with parents of TD children. The Mann-Whitney U test indicated that there was no significant difference between the two groups (Median=8.00, U= 984.50, p=.57).

It is hypothesised that parental anxiety would be associated with higher rates of dental anxiety in both groups

Spearman's Rho correlation was conducted between Hospital Anxiety and Depression Scale using only the anxiety subscale (HADSA) and Children's Fear Survey Schedule-Dental Sub-scale (CFSS-DS). Children with ASD showed a significant relationship between their parents' anxiety and their own dental anxiety (r=.39, p=.01). This shows that having higher levels of dental anxiety in children with ASD is associated with having an anxious parent in general. The results show that there is no significant relationship between these variables in TD children (r=.20, p=.18). This implies that having higher levels of dental anxiety in TD children is not associated with parents' anxiety.

The strength of the correlation for the ASD group was compared to the correlation for the TD group using Fisher r-to-z transformation, which shows no difference between the two groups.

Next, gender and ethnicity were controlled in the relationship between parents' anxiety (HADSA) and children's dental anxiety (CFSS-DS). The partial correlation showed a significant relationship between children with ASD and their parents' anxiety (r=.43, p=.00), while TD children had no significant relationship between their parents' anxiety and their own dental anxiety (r=.19, p=.21). The results did not differ from the initial correlation where gender and ethnicity were not controlled and the same associations were reported.

Norman Corah's Dental Questionnaire

This questionnaire is used to measure the parents' dental anxiety. A Mann-Whitney U test was performed to compare parents of children with ASD with parents of TD children. The Mann-Whitney U test indicated that there is no significant difference between the two groups (U= 875.50, p=.15).

It is hypothesised that parental dental anxiety would be associated with higher rates of dental anxiety in both groups

A Spearman's Rho correlation was carried out parents' Dental Anxiety Scale (DAS) and Children's Fear Survey Schedule - Dental sub-scale (CFSS-DS). Children with ASD demonstrated a significant relationship between their parents' dental anxiety and their own dental anxiety (r = .39, p=.01). TD children also showed a significant correlation between their parents' dental anxiety and their own dental anxiety (r = .41, $p<.004$). The results of the correlations show that higher levels of dental anxiety in both groups (ASD and TD) is associated with having dentally anxious parents.

The strength of the correlation for the ASD group was compared to the correlation for the TD group using Fisher r-to-z transformation, which shows no difference between the two groups. Moreover, a partial correlation was conducted controlling for gender and ethnicity in the relationship between parents' dental anxiety (DAS) and children's dental anxiety (CFSS-DS).

Table 5.25: Relationship between DAS and CFSS-DS when controlling for ethnicity and gender

Controlled variables	**Item**	**Group**	***Partial Spearman's Rho Correlation***	
			R	*P*
Gender and Ethnicity	**DAS**	ASD	.30	.05
		TD	.45	.00

The results demonstrated significant association between both children with ASD and TD children and their parents' dental anxiety, which is similar to the results of the correlations carried out without controlling gender and ethnicity.

5.9 Predicting Dental Anxiety

A series of multiple regression analyses was carried out using the forward selection method to predict level of dental anxiety as measured by the CFSS-DS. Each regression tested one factor, which is represented by a questionnaire and its sub-scales, except for the Hospital Anxiety and Depression Scale, Dental Anxiety Scale, and the total of Spence Children Anxiety Scale (Totalscas); they were grouped together in one analysis. In addition, the groups (ASD and TD) were tested with each factor. And the Children's Fear Survey Schedule - Dental Sub-scale (CFSS-DS) was used as an independent factor in all regressions. The results are shown below. The following section presents the results of the analyses.

5.9.1 Demographics

Multiple regression analysis was used to test if the demographic variables (Gender, Ethnicity, Age), in addition to the groups (ASD and TD), significantly predicted participants' dental anxiety. The results of the regression indicated that two predictors explained 13% of the variance (R^2=.13, R^2Adjusted = .11, F (2,89) = 6.86, p=.002).

It was found that gender significantly predicts dental anxiety (β = 8.36, p=.003). It was also found that the different groups (ASD, TD) significantly predict dental anxiety (β = 7.82, p=.01). Nevertheless, ethnicity did not significantly predict dental anxiety.

5.9.2 Spence Children's Anxiety Scale (SCAS)

Multiple regression analysis was used to test if the Spence Children's Anxiety Scale (SCAS) sub-scales (physical injury, social phobia, generalized anxiety, and panic/agoraphobia) and the groups (ASD and TD) significantly predicted participants' dental anxiety. The results

of the regression indicated that one predictor explained 35% of the variance (R^2=.35, R^2Adjusted = .35, F (1,90) =48.94, p<.001).

It was found that physical injury significantly predicted dental anxiety (β = .59, p<.001). It was also found that the different groups (ASD, TD) showed a trend (β = .15, p=.08), as well as panic/agoraphobia (β = .20, p=.06). Nevertheless, social phobia and general anxiety did not significantly predict dental anxiety.

5.9.3 Sensory Profile

Multiple regression analysis was used to test if the Sensory Profile (SP) and the different groups (ASD and TD) significantly predicted participants' dental anxiety. The results of the regression indicated that one predictor explained 30% of the variance (R^2=.30, R^2Adjusted = .30, F (1,90) =39.31, p<.001). It was found that sensory sensitivity significantly predicts dental anxiety (β = .55, p<.001). It was also found that different groups (ASD and TD), low registration, sensation seeking, and sensation avoiding did not predict dental anxiety.

5.9.4 Dental Cognitive Questionnaire (DCQ)

Multiple regression analysis was used to test if the Dental Cognitive Questionnaire (DCQ) and the groups significantly predicted participants' dental anxiety. The results of the regression indicated the one predictor explained 52% of the variance (R^2=.52, R^2Adjusted = .52, F(1,90)=98.30, p<.001). It was found that worries about treatment (DCQC) significantly predicted dental anxiety (β = .72, p<.001). It was also found that, for the different groups (ASD, TD), worries about the dentist (DCQA), and worries about self (DCQB) did not predict dental anxiety.

5.9.5 Dental Experiences Questionnaire (DEQ)

Multiple regression analysis was used to test if the Dental Experiences Questionnaire (DEQ) and the two groups significantly predicted participants' dental anxiety. The results of the

regression indicated that the two predictors explained 18% of the variance (R^2=.18, R^2Adjusted = .16, F(1,89)=9.47, p=.003).

It was found that receiving basic treatments significantly predicted dental anxiety (negative prediction) (β = -.32, p=.001), which means the more a dentist is visited the less dental anxiety applies. It was also found that unpleasant experiences significantly predicted dental anxiety (β = .30, p=.003). Receiving advanced treatments show a strong trend (negative) (β = -.19, p=05). Nevertheless, the groups (ASD and TD), painful experiences, and worrying things that the child might have heard or seen did not significantly predict dental anxiety.

5.9.6 Overall Anxiety and Parents' Anxiety

Multiple regression analysis was used to test if the different sources of anxiety (Totalscas, HADSA, DAS) and the different groups (ASD and TD) significantly predicted participants' dental anxiety. The results of the regression indicated that the two predictors explained 41% of the variance (R^2=.41, R^2Adjusted = .40, F(1,89)= 30.75, p=.001). The Spence Children's Anxiety Scale (SCAS) total score significantly predicted dental anxiety (β = .52, p<.001). Also, parent's Dental Anxiety significantly predicted dental anxiety (β = .29, p=.001). Nevertheless, different groups (ASD and TD) and parents' general anxiety (HADS) did not significantly predict dental anxiety.

5.9.7 Summary

The factors that predicted dental anxiety for children with ASD and TD children after carrying out the regression are shown in figure 5.1, and they are the following:

- Gender
- Physical injury sub-scale of the Spence Children'sAnxiety Scale
- Sensory Sensitivity sub-scale of the Sensory Profile
- Worries about treatment sub-scale (DCQC) of the Dental Cognitive Questionnaire

- Receiving basic treatment sub-scale (DEQA_1) of the Dental Experience Questionnaire
- Unpleasant past experience sub-scale (DEQB) of the Dental Experience Questionnaire
- Parent's dental anxiety from the Norman's Dental Anxiety Scale

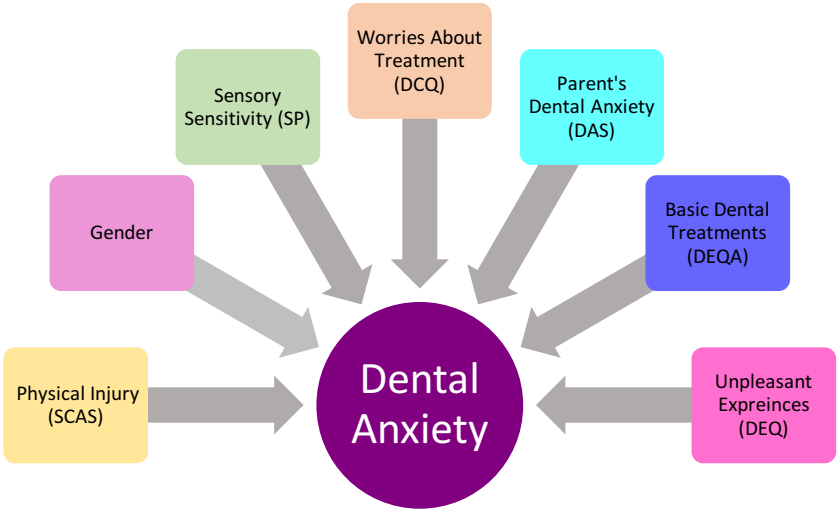


Figure 5.1 Diagram to show the statistically significant predictors for both ASD and TD children, which are derived from the multiple regression analyses described above (Section 5.9).

5.10 Predicting Dental Anxiety with an Exploratory Regression

An exploratory regression was carried out using the significant predictors derived from the multiple regression described above, bearing in mind that the different groups (ASD and TD) were only a predictor for dental anxiety when combined with the demographics in the previous regression. Therefore, it is not included here as a factor that can influence the development of dental anxiety. However, the data was split by groups to ascertain whether dental anxiety is predicted by the same factors for both groups or not.

The factors that were included were: physical injury as measured by the Spence Children's Anxiety Scale, sensory sensitivities according to the Sensory Profile, worries about treatment drawn from the Dental Cognitive questionnaire, receiving basic treatment and unpleasant experiences based on the Dental Experiences Questionnaire; and parents' dental anxiety from Norman's Dental Anxiety Scale. The data analyses were carried out to assess the

relative contribution of different factors for each group. Data were split by group (ASD and TD) and the forward selection method was used to predict dental anxiety as measured by the CFSS-DS.

The results of the regression for the children with ASD indicated that the three predictors explained 74% of the variance (R^2=.74, R^2Adjusted = .72, F (3,41) =38.09, p<.001). It finds that worries about the treatment (DCQC) significantly predicted dental anxiety (β = .57, p<.001), as well as receiving basic dental treatments (β = -.22, p=.01), which negatively predicted dental anxiety and that means the more the dentist is visited the less anxious the person feels. In addition, physical injury also predicts dental anxiety in children with ASD (β = .28, p=.01). Nevertheless, parents' dental anxiety, unpleasant experiences, and sensory sensitivity do not significantly predict dental anxiety for children with ASD.

The results indicate that, for TD children, one factor explains 34% of the variance (R^2=.34, R^2Adjusted = .32, F(1,45) =23.09, p<.001). It shows that worries about the treatment (DCQC) significantly predicted dental anxiety (β = .58, p<.001) while parents' dental anxiety shows a strong trend (β = .24, p=.06). However, physical injury, receiving basic dental treatment, unpleasant experiences, and sensory sensitivity do not significantly predict dental anxiety for TD children.

5.11 Discussion

This study contributes to the understanding of dental anxiety in children with ASD in comparison to TD children. The findings show that children with ASD have higher levels of dental anxiety, anxiety in general, a different sensory profile, and a different range of dental experiences but do not differ in rates of dental cognition, parents' anxiety or parents' dental anxiety.

As might be expected, between groups comparison shows that there is a difference between TD children and children with ASD concerning dental anxiety, and that children with

ASD present an increased level of dental anxiety in comparison to TD children. This is consistent with other studies in this field (Lai et al., 2012; Mayes et al., 2012). For example, in a study conducted by Stein et al. (2014), children with ASD exhibited significantly greater behavioural distress during routine dental care, compared with their TD counterparts.

Nevertheless, when overall anxiety is controlled, children with ASD show similar levels of dental fear as TD children; this is explained by the greater rates of anxiety in general that children with ASD demonstrate and also that anxiety in general and dental anxiety are correlated. It also calls into question the manifestation of anxiety in children with ASD. Clearly, children with ASD exhibit different behaviours to TD children and they understand the world in a different way, so there remain questions why children with ASD feel anxious about the dentist and what their anxious perceptions are. There may be a thin line between general anxiety and dental anxiety (Paryab & Hosseinbor, 2013) and that no individual factor could solely explain the development of dental anxiety (Nigam et al., 2013). It is noted that there is currently a lack of research into the issue of dental anxiety in the particular case of children with ASD.

In addition, it is seen from the results that the ASD and TD sample seem to indicate similar levels of fear about different variables that arise during dental treatment. For most of the items listed on the CFSS-DS, there is no difference between the groups, which is unexpected. The only difference was in reported anxiety about the experience of having somebody examine the mouth, which indicates increased levels of fear for ASD youngsters. This could be explained by the children with ASD having heightened sensory sensitivity.

The researcher used the Spence Children's Anxiety Scale to assess anxiety in general in both groups. Between group comparison show that children with ASD have higher rates of panic/agoraphobia, separation anxiety and obsessive compulsive disorder than TD children, which could explain some of their overall high rates of anxiety (White et al., 2009). The children with ASD and TD children show the same levels of general anxiety and social phobia, which

conflicts with existing literature that has found that children with ASD routinely score higher than TD children on all the SCAS subscales (Magiati, Chan, Tan, & Poon, 2014; Ozsivadjian et al., 2014).

It is unclear why the present study finds inconsistent results in this case. For example, the study by Ozsivadjian et al. (2014) studied 30 children with ASD and, as such, had an approximately similar sample size to the present study. These unusual findings could be attributed to the small size of the samples used in general and also to sampling and the variations in the make-up of the study participants.

As previously noted, anxiety in general is correlated with dental anxiety in children with ASD, which is what the researcher found when she controlled overall anxiety to discover the levels of dental anxiety in both groups. A correlation was then carried out between other forms of anxiety and dental anxiety, which showed that children with ASD's dental anxiety was associated with pain/agoraphobia, physical injury, and generalized anxiety. These factors could be explained by the fact that some questions in the different measures ask the same question; for example, in the SCAS one of the questions is "I am scared of going to the doctor's or dentist's" and that is the same as item 1 and 2 in the CFSS-DS. The overlap in the questions can explain some of the correlation. In addition, a partial correlation was carried out controlling for ethnicity and gender. However, children with ASD showed similar correlations between dental anxiety and other forms of anxiety, which were pain/agoraphobia, physical injury, and generalized anxiety. This could be explained by the fact that being of a particular gender or ethnicity does not affect the way other forms of anxieties are related to dental anxiety.

Studies have shown that behaviours manifested by ASD and anxiety can cross over and therefore that the same behaviours may be present in both disorders (Richman, Dotson, Rose, Thompson, & Abby, 2012; Zainal et al., 2014). However, the present researcher has not found relevant recent literature that examines the relationship between specific forms of anxiety and dental anxiety in children who have ASD.

TD children and children's dental anxiety showed association with social phobia, physical injury and generalised anxiety, which did not differ significantly from children with ASD. Nevertheless, the results suggest that there could be a meaningful difference between the two groups, but there was not sufficient data to conclude a statistical significance, especially in panic/agoraphobia and physical injury fears. Nevertheless, when controlling for gender and ethnicity, TD children display the same correlation except for social anxiety, and the association between social and dental anxiety disappears.

Between groups comparison using the Dental Cognitions Questionnaire (DCQ) showed that the children with ASD and TD children did not differ in terms of their worries about the dentist, self or dental treatment. From a search for relevant literature on this issue, it became apparent that few recent studies have been conducted using the DCQ and no studies currently exist that have applied the DCQ to children with ASD, or compared findings between an ASD and a TD child sample. In this respect, the present study contributes to current understanding of this issue. Some recent studies, such as the research conducted by Carrillo-Diaz et al. (2013), employed the DCQ to assess the efficacy of cognitive and non-cognitive factors on dental anxiety.

In terms of the correlation between dental anxiety and cognitions, the present study confirms that there is a correlation between thoughts about the dentist and dental visits for both groups of children. The findings confirm the existing literature regarding TD children, which found that cognitions significantly affect dental fear scores. For example, people with anxiety may overestimate the pain, discomfort, and negative events that will be experienced; (Carrillo-Diaz et al., 2012; Ramos-Jorge et al., 2013) and they may view this as inevitable. This was an interesting finding regarding children with ASD as it was not reported or considered in depth previously as a cause for dental anxiety. Therefore, the quantitative study examined the cognitions to determine if it is a predictor for dental anxiety.

The researcher considered the difference between the two groups in the sensory profile, and found that children with ASD are significantly different from TD children in the way they process sensory stimuli. The association between dental anxiety and sensory profile was examined and findings show that dental anxiety in children with ASD is associated with low registration, sensory sensitivity, and sensation avoiding. In TD children, dental anxiety is only associated with sensory sensitivity.

Previous research reports that children with ASD present greater sensory sensitivity than TD children (O'Donnell, Deitz, Kartin, Nalty, & Dawson, 2012; Stewart et al., 2016). However, much existing research used different sample populations which make comparisons difficult in view of the wide variety of methodological approaches employed by each study (Cole & Edwards, 2015).

These findings confirm existing literature in this field (Stein et al., 2011). The literature generally finds that children with ASD have a higher sensitivity to sensory stimuli. For example, research conducted by Cermak et al. (2015) found that difficulties with sensory processing are prevalent in up to 95% of children with ASD. This is important since sensory responsivity affects the quality of dental treatment and makes it more difficult for dentists to cure problems (Stein et al., 2013). In the present study, it is found that both groups show that their dental anxiety is related to their tendency to be over responsive to sensory stimuli and information. This is an interesting area of research, particularly because it has implications for both ASD and TD children.

A between groups comparison was carried out to compare previous dental experience using the Dental Experience Questionnaire, which is a questionnaire developed by the researcher. The findings show that children with ASD and TD children do not differ in the receipt of basic treatment, such as check-ups and cleaning, number of painful experiences, and the worries they have from things they have heard or seen. Nevertheless, there is a difference in the number of unpleasant experiences reported by children with ASD. Also, the receipt of

advanced treatments, such as root canals, is different, and TD children reported higher numbers of such advanced treatments. The correlation between dental anxiety and dental experience was different for each group. Dental anxiety in children with ASD was negatively linked to the receipt of basic dental treatment while, in TD children, dental anxiety was associated with unpleasant experiences, painful experiences, and worrying things that the child might have heard or seen.

The relationship between previous negative experience and dental anxiety for TD children and these results support previous literature (Carrillo-Diaz et al., 2013; Nigam et al., 2013). Studies have found correlations between past negative experience and dental anxiety (Ramos-Jorge et al., 2013). These could be the result of learned responses to pain (Appukuttan et al., 2013), but also personality traits or biological dispositions (Carrillo-Diaz et al., 2013). The literature tends to confirm that previous negative experiences result in greater dental anxiety (Storjord, Teodorsen, Bergdahl, Wynn, & Johnsen, 2014).

From the findings, there is a noticeable difference in terms of the ASD sample, which shows that dental anxiety in children with ASD negatively correlates to frequency of receiving basic treatments (check-ups & cleaning), which means that the more the child receives basic treatment the less anxious they are. This is not the case for TD children where the findings showed that their dental anxiety is linked to having had unpleasant experience, painful experience and having heard or seen something about the dentist that worried them. This is an interesting finding because the researcher speculates that children with ASD in this sample either have good teeth or do not receive treatments as often as TD children, therefore they do not report as many painful or unpleasant experiences as TD children. Moreover, it could also be that children with ASD did not read the questions and just chose random answers, or that they did not understand the questions.

In terms of practice, dentists are generally aware of the need to avoid problems during treatment, since the perception of negative experience is considered problematic for the general population. Many dental procedures might involve a degree of pain, yet not all people develop

dental anxiety. As such, the relationship between previous painful experience and dental anxiety may be more complex (Storjord et al., 2014).

The current study addressed parents' anxiety in both groups and how it correlates with dental anxiety using the Hospital Anxiety and Depression Scale (HADS). It is worth mentioning that not all participants were anxious, as it was not one of the recruiting criteria. A between groups comparison showed that there is no difference in the anxiety of parents of TD children and parents of children with ASD. This is an unexpected finding as previous research has consistently found that parental stress and anxiety are higher among parents of children with ASD, due to the greater demands placed upon them by the disability (Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaidan, 2013). Questions arise in terms of the experience of the parents in the current study. The findings could be due to methodological errors in the present research. It is also possible the particular parents had developed coping techniques that enabled them to successfully cope with and manage children with ASD. As such, this would be an interesting area for further research.

When looking at the association between the parents' anxiety and dental anxiety, unlike the findings of a number of studies (Olak et al., 2013), the present research did not find a correlation between dental anxiety in TD children and parental anxiety. Given this variance from established research, this may be considered to be an unusual finding for the present research. The study does, however, finds a relationship between dental anxiety in children with ASD and the anxiety of their parents. Several studies have indicated there is a link between parental and child anxiety (Nigam et al., 2013), although much of the research into this field is contradictory (Krikken, van Wijk, ten Cate, & Veerkamp, 2013).

As discussed in the literature review, parental behaviour and responses to anxious situations can affect their children through modelling and genetics (Wood et al., 2013). This may be particularly important, given that parents of children with ASD are more likely to suffer from stress because their child has ASD (Delli et al., 2013). It is unclear why this was only found to be present in the ASD sample. It could also be because a higher number of the sample

were from the UK, suggesting there are different degrees of influence from their parents as a feature of cultural behaviour. It could also be because parents of children with autism are more inclined to demonstrate stress, most likely as a result of the long-term challenges that autism involves (Seymour, Wood, Giallo, & Jellett, 2013), or it could be because the samples were small and there was not enough variance in the TD children sample.

The researcher used the Norman Corah Dental Questionnaire to study parents' dental anxiety in both groups and its association with dental anxiety in general. A between groups comparison demonstrated that there is no significant difference in the dental anxiety of parents of TD children and parents of children with ASD. Although the Corah Scale has been used widely to measure dental anxiety, (Dikshit, Limbu, & Bhattarai, 2013), studies applying this scale to parental experiences are not numerous to date (Alaki et al., 2012). The present study, therefore, contributes to an understanding of parental experience with regard to children with ASD.

The association of parents' dental anxiety with their child's dental anxiety was tested. Unlike the rest of the data, the study found that parental dental anxiety is associated with dental anxiety in ASD and TD children. The present findings are consistent with previous research in this respect (Carrillo-Diaz et al., 2013; Coric et al., 2014; Dikshit et al., 2013). It is unclear why the study accords with existing literature in this respect but not in terms of the parents' anxiety in general. It could suggest that the sample used is not proportionate to the general population.

5.11.1 Controlling for Ethnicity and Gender

A correlation was carried out between age and all of the measures, which demonstrated that age does not have a significant effect. On the other hand, ethnicity and gender showed a significant effect on several measures. Therefore, they were controlled for in all the measure to determine their effect on the results.

Using the CFSS-DS, children with ASD showed higher levels of dental anxiety than TD children when ethnicity and gender were controlled using an ANCOVA, which is similar to

what has been found earlier (Section 5.8.3). This could be justified by saying that children with ASD have higher dental anxiety whether they are boys or girls and whether they were British, Caucasian, or Arab.

Moreover, partial correlations were carried out on SCAS, Sensory Profile, DCQ, DEQ, HADS, and DAS. The findings showed that controlling gender and ethnicity did not have a significant effect on the results as most of them were similar to the initial correlations that were carried out (Section 5.8.3). However, there were a few significant correlations that diminished after controlling for gender and ethnicity, namely social anxiety in TD children and worries about self in children with ASD.

However, having almost similar results after controlling for gender and ethnicity shows that having dental anxiety or other forms of anxiety associated with it is not affected by ethnic background or gender.

5.11.2 Predicting Dental Anxiety

The present study looked at possible factors that predict dental anxiety using multiple regression. The researcher conducted multiple regression using the Demographics, Spence Children's Anxiety Scale, Sensory Profile, Dental Cognitive Questionnaire, Dental Experience Questionnaire, parental anxiety, and parents' dental anxiety, in addition to the groups (ASD and TD) as independent factors. The CFSS-DS was used as the dependent variable throughout all regressions, which enabled the researcher to predict dental anxiety. Multiple regression was conducted on the data, where all factors were tested separately using the forward method to explore the possible predictors for dental anxiety. The findings from the first exploratory regression have been illustrated in the results (Section 5.9). The results from the initial regression analysis, that was completed by adding grouped variables along with the different groups (ASD and TD), demonstrate that dental anxiety is predicted by development, gender, physical injuries, sensory sensitivity, worries about treatment, the amount of basic treatments that have been received, unpleasant experience, overall anxiety, and parents' dental anxiety.

The present findings fit well with previous research. The results show that physical injury predicts dental anxiety, which is explained in previous research by the role of the child's perception of pain on dental anxiety (Ramos-Jorge et al., 2013) and also the intolerance that children with ASD have regarding physical pain (Courtemanche & Black, 2016). Moreover, sensory sensitivity has been found to predict dental anxiety for both groups in this study, which is interesting as it is well known from previous research that children with ASD have a more unusual response to stimuli than TD children (Kuhaneck & Chisholm, 2012). Sensory sensitivity was expected to be a predictor for children with ASD as it is recognised that children with ASD exhibit co-occurring sensory processing problems and studies have found the prevalence of sensory problems in children with ASD to be up to 80% (Ben-Sasson et al., 2009), but not for TD children.

The findings also show that dental anxiety is predicted by worries about treatment, which relates to the cognitions of the child. Previous research has demonstrated that cognitive vulnerability and oral health are key mediating variables in the occurrence of dental anxiety in TD children (Carrillo-Diaz et al., 2012), but this was not that case for children with ASD. Therefore, this was an interesting finding regarding children with ASD, and could be explained by the use of questionnaires that made it easier for children with ASD to express their thoughts when choosing an existing answer.

Dental anxiety was predicted negatively by the receipt of basic treatment, such as check-ups and cleaning, which means the more they receive treatment the less anxious they are. This could be explained by the preference of children with ASD for routine and familiarity and it was suggested that individuals with ASD may need to visit the dentist several times before receiving treatment in order to become familiar with the environment (Klein & Nowak, 1998). In addition, unpleasant experiences also predict anxiety which, as noted in previous literature, can be particularly distressing for TD children, let alone those with ASD. These negative conclusions are not specifically due to the ASD but rather to events witnessed during dental

visits and due to a relative inability to process such experiences (Chalfant, 2011), together with a predisposition to experience greater anxiety in general (Cocia et al., 2012; Farrugia & Hudson, 2006).

It is also reported that parental dental anxiety predicts dental anxiety, which is supported by previous research that found that the impact of parental anxiety may be due to hereditary genetic factors, but also due to learning, parenting styles and parental personality traits (Krikken et al., 2010). As discussed, parental dental anxiety and, consequently, their anxious behaviours impact on children through modelling (Armfield & Heaton, 2013; Wood, McLeod, Sigman, Hwang, & Chu, 2013), but genetic factors may also be involved (Coric et al., 2014). Given the central role that parents can play in their children's anxiety, there is much scope for parents to become more aware of the beneficial effects that proper modelling may have in reducing their child's concerns, which can involve watching relatives undergo dental treatment without fearful or negative reactions (Armfield & Heaton, 2013).

Some studies have investigated the genetic aspects of dental anxiety (Ray, Wide Boman, Bodin, & Berggren et al., 2010) and have confirmed the significance of these factors as well. For example, the study by Randall et al. (2016) found that dental fear was 30% heritable and the fear of pain was 34% heritable. They also found a substantial genetic correlation between dental fear and fear of pain.

Findings from the multiple regressions show that the diagnostic groups did not predict dental anxiety, which means having ASD or not does not predict dental anxiety in this sample. This is an interesting finding, as the researcher expected that having ASD would make them more prone to developing dental anxiety. However, this finding could be due to the small sample size.

5.11.3 Predicting Anxiety using Exploratory Regression

The researcher performed a second multiple regression that tested only the factors that predicted dental anxiety from the first regression using the forward method. Although different

groups (ASD and TD) did predict dental anxiety when grouped with the demographic variables but did not predict dental anxiety when grouped with other factors. They were not included in the analysis as a factor but the data were split according to groups. This enabled the researcher to see the different predictors for each group and to examine whether dental anxiety is predicted by the same or different factors for each group.

The researcher carried out a regression using the forward method and the predictors for dental anxiety from the previous regression (see Section 5.9). The findings showed that the two groups (ASD and TD) differed in their dental anxiety and what predicts it. Significantly, the findings show three predictors of dental anxiety for children with ASD, and these explained 74% of the variance in factors that predict dental anxiety. It was found that worries about treatment predict dental anxiety, which was an unexpected finding for children with ASD. Worries about treatment can be linked to information processing abilities in children with ASD. The literature has shown that children with ASD demonstrate a reduced ability to interpret their environment (O'Nions et al., 2014) and that their low ability to self-monitor and control impulses may be due to weaknesses in executive functioning (Moraine, 2015; Snyder, Miyake, & Hankin, 2015). Moreover, physical injury fears and the receipt of basic dental visits also predict dental anxiety.

Previous research has noted that dental anxiety could be influenced by the perception of pain and that a lesser tolerance of pain may increase anxiety (Ramos-Jorge et al., 2013). Sensitivity to pain may also be related to previous experiences or negative anticipation of physical injury and, in this respect, existing research has found there is a strong relationship between previous painful experiences during dental treatments and dental anxiety (Blomqvist et al., 2014). Also, the findings of the current study indicate that children with ASD become less anxious as the number of times they visit the dentist increases. In this respect, research has found that the regularity of dental visits can affect dental anxiety, perhaps because it results in more significant treatment needs (Paryab & Hosseinbor, 2013). Dental anxiety in TD children was found to be

predicted by one factor, which is worries about treatment and this explained 34% of the variance.

5.11.4 Conclusion

In conclusion, children with ASD reported higher dental anxiety than TD children. Comparisons between children with ASD and TD children showed that children with ASD were different in anxiety overall, sensory profile, and in some of their dental experiences. Nevertheless, no difference was reported regarding cognitions, parents' anxiety, and parents' dental anxiety.

Moreover, the researcher has completed another regression, which was exploratory and included only the factors that predicted dental anxiety in the first regression. The findings show that children with ASD differ from TD children in the factors that predict their dental anxiety.

Since the factors that were tested in this study were chosen based on the first and second qualitative studies, this study confirms, through analysis, the respondents' views. The need to understand all three studies as one will be discussed in the following chapter.

6 Chapter Six

Three as One: General Discussion

The present thesis examines dental anxiety in individuals with ASD. The study was motivated by the researcher's personal interest in the oral health of children with ASD, and the fact that these ASD-related challenges can lead to children with ASD having poorer standards of oral health than equivalent TD populations (Cagetti et al., 2015; Delli et al., 2013; Jaber, 2011; Ljaljevic et al., 2012; Loo et al., 2009). This thesis presents interesting findings, such as that sensory sensitivities affect dental anxiety in TD children as much as children with ASD. Moreover, it shows that cognitions play an essential role in the development of dental anxiety in children with ASD. Also, it shows that being ASD or TD does not predict dental anxiety.

Little has been documented about what individuals with ASD report about their own dental anxiety. Recent research emphasises the importance of the voice of those who have ASD (Harrington, Foster, Rodger, & Ashburner, 2014; Healy, Msetfi, & Gallagher, 2013; Liu, Carter, Boehm, Annandale, & Taylor, 2014; Parsons, 2014). Moreover, there is limited literature that involves individuals with ASD themselves in research, particularly about their own experiences, views, thoughts and anxieties about dentists. This thesis does not rely solely on parents to report the experiences of dental anxieties in their children, but it also includes reports that are completed by the individuals themselves.

Previous research exploring dental anxiety has tended to be mainly based on TD participants, with only a few comparing individuals with ASD and TD children. Most of these studies tended to focus on adults (Blomqvist et al., 2014). Therefore, this thesis offers a wider understanding of the immediate experience of those individuals with ASD concerning their personal experiences with the dentists along with their anxieties.

According to the Wood and Gadow (2011) model, different ASD stressors can contribute to the development of dental anxiety, such as the unpredictability of the dental visits and what will happen there, the long interval between visits which means a break in routine, and aversive sensory stimuli such as the sound of the drill. These stressors result in the development of anxiety and increased ASD symptoms, as shown in the current research. As reported in the current thesis, some of the individuals with ASD showed increased dental anxiety while others avoided dental visits, which resulted in poor oral health and reduced quality of life. Figure 6.1, below, demonstrates some of the ASD related stressors that were reported in the current research (studies 1, 2 and 3) and how they affect dental anxiety.

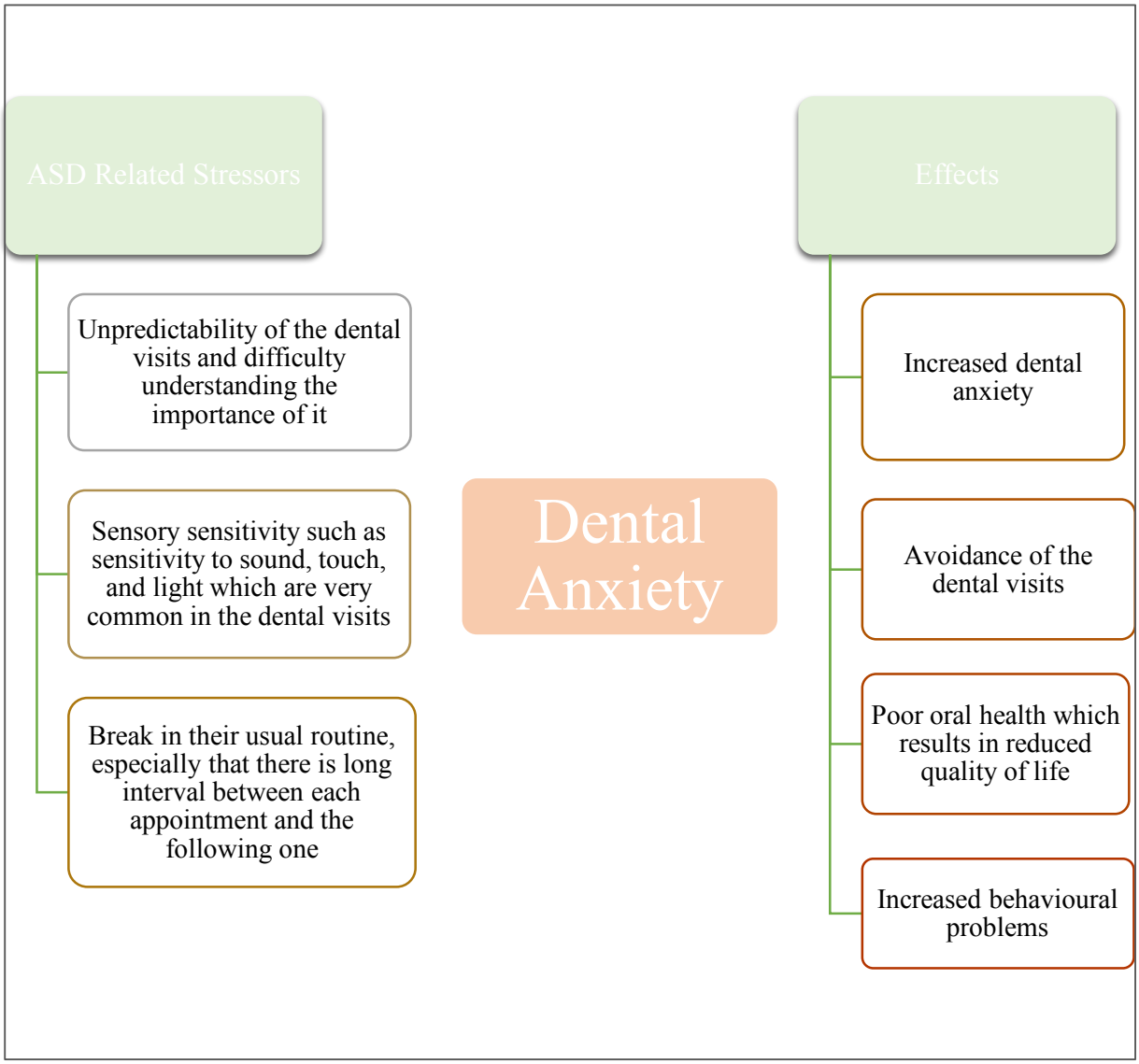


Fig 6.1: Model created from the findings of the current research and based on Wood and Gadow (2011) model

In response to the research question, the first qualitative study (Chapter 3) discovered a range of common and general reasons for dental anxiety: fear of the unknown, family history of dental fear and anxiety, worries about what other people or the dentist may think of their teeth, negative thoughts about the dentist, previous negative experiences and worries about the pain. Several of these causes arose as problematic in terms of both dental anxiety (first theme) and other anxieties (second theme). The thematic coding revealed these issues were experienced by several individuals who had visited different dentists, which suggests these experiences were common during dental treatment and, in this respect, the present study can generalise the findings to the general population to a degree.

The second qualitative study (Chapter 4) set out to answer the research questions from a different perspective. Again, the thematic process could identify beliefs about the causes of dental anxiety held by dentists because they have an important role to play in terms of influencing future treatment and creating dental awareness (Pandya et al., 2016), which is why it was important to get their views. In terms of the research question, the dentists identified various issues that they considered to be the causes of dental anxiety. Some of these had been identified in the first study, namely: worries about feeling pain (which one dentist thought would be particularly severe for children), previous negative experiences, fear of the unknown, and sensory sensitivity. They also thought that parental anxiety could influence children's anxiety, which was found in the first qualitative study.

Some interesting findings arise from the comparison between the first and second studies. For example, dentists consider that negative information transmission is a cause of dental anxiety, although this was not mentioned by the individuals with ASD themselves, or by the parents. One possible explanation is that dentists see large groups of patients with varying experiences, while parents of children with ASD and individuals with ASD of course only have information about themselves, and negative information transmission may not have been a factor in this volunteer sample. Another possibility is that they were not aware of what they do in this context.

The third study (Chapter 5) brought together the data collected by the two previous studies, with some important exclusions, and, once the factors that affect dental anxiety for individuals with ASD were identified, they were compared between ASD and TD populations. The comparison with a TD population was important to identify the impact of ASD and this added yet another dimension to the results. As discussed in the literature review, individuals with ASD have a tendency to encounter greater degrees of anxiety in general (Cagetti et al., 2015; Grondhuis & Aman 2012; Mayes et al., 2012), as well as dental anxiety (Blomqvist et al., 2014).

The findings from both qualitative studies provide the basis for this third study. The third study examines the impact of other forms of anxiety, namely, sensory processing, past negative experience, and thoughts and worries about the dentist, as well as the impact of parental anxiety and parental dental anxiety.

The third study finds some similarities between the ASD and TD groups, but also some differences: children with ASD had higher levels of dental anxiety and anxiety in general, a different sensory profile and reported more negative dental experiences than their TD peers. Children with ASD demonstrated similar fears regarding aspects of dental treatment as TD children. However, there were no differences in dental cognitions, parental anxiety or parental dental anxiety.

Dental anxiety correlates with different factors in children with ASD and TD. For both groups, dental anxiety correlates with dental cognitions, sensory sensitivity, physical injury, generalised anxiety, unpleasant experiences, and parents' dental anxiety. However, dental anxiety in ASD also correlates with panic/agoraphobia, low registration, sensation-avoiding, receipt of basic treatment, and their parents' anxiety in general. In contrast, for TD children, their dental anxiety is correlated with social phobia, painful experiences, and worrying things that they might have heard or seen (see Section 5.8.3 for more details).

To explore predictors of anxiety, a series of regression analyses were carried out where groups of related variables, as well as diagnostic groups (ASD and TD), were entered into the

analyses. Interestingly, in no analysis did diagnostic group predict dental anxiety. However, dental anxiety was predicted for both groups by physical injury fears, sensory sensitivities, worries about treatment, the frequency of basic treatment, unpleasant experiences, anxiety overall and parental dental anxiety.

Finally, exploratory regression examined factors that were found to predict dental anxiety in the first regressions. ASD and TD groups were examined separately. Findings show that the different groups had different predictors for dental anxiety. Children with ASD had three predictors for dental anxiety, which explained 74% of the variance: worries about treatment, physical injury fears, and the receipt of basic treatment. In both groups, worries about treatment predicted dental anxiety. However, TD children had only one predictor that accounted for 34% of the variance, which was worries about treatment.

While there is evidence in the literature that sensory sensitivity causes are important in terms of anxiety and ASD (Mazurek et al., 2012; Shapiro et al., 2009; Stein et al., 2011), this variable does not predict dental anxiety for ASD groups in the exploratory regression. This is a surprising finding, since sensory sensitivity is found to be a predictor in the first regression and it was repeatedly highlighted in the first two qualitative studies as a relevant variable. It is unclear why this finding emerged in the exploratory regression. It is possible that it is less important than the other factors that were measured, but this finding needs to be replicated with a larger sample.

In summary, the current thesis has examined the experience of dental anxiety in individuals with ASD from several perspectives. The research notes that individuals with ASD have a different experience of dental anxiety than TD groups, although there are not as many differences as predicted. The present research confirms findings in the existing literature, but also raises questions as to why its findings diverge from the expected findings in some respects.

6.1 Limitations of the Study

While the researcher is aware of the need for designing a rigorous from the start, some limitations were revealed during the process, which are discussed below.

6.1.1 Sample

The researcher had difficulty finding participants for the third study. There were also a number of abnormalities with the sample which are outlined below. Consequently, the results could be affected by the small sample size that the researcher managed to recruit. The data are likely to be underpowered.

6.1.2 Age

As can be seen from the results of the third study, the mean age of the children with ASD was 164.76 months, whereas for TD children it was 176.94 months, meaning the TD children were roughly one year older than the ASD sample. According to the literature, age is considered to be a factor that can affect anxiety (Jovanovic et al., 2014; Vasa et al., 2013). Some research has found that anxiety decreases with age (Nigam et al., 2013) and this suggests anxiety is proportional to age (Gotham, Bishop, Hus, Huerta, & Lund et al., 2013). Importantly, other studies have found variations, such as that of van Steensel, Bogels and Perrin (2011), which showed that children with ASD with a higher mean age demonstrated higher levels of anxiety.

6.1.3 Ethnicity

In the second qualitative study, a mix of ethnicities was represented. There were four Dutch and one Arab dentist, in addition to the two English dentists. While this cultural mix might be an advantage in helping to articulate a variety of views, English was not the first language for many of the participants. However, all but one of the Dutch participants were fluent in English. This particular group had a special interest and expertise in paediatric dentistry involving children with autism, and it was felt that their experiences were too important to omit.

In the third study, the sample included participants from the UK and Saudi Arabia, as well as other ethnic backgrounds. The sample was unevenly distributed in terms of ethnicity; as there were a number of Arab participants in the TD group, while none of the participants in the ASD

group were Arab. Although all of the participants were resident in the UK, ethnicity may impact on dental anxiety in various ways. For example, there may be different cultural attitudes towards the importance of oral hygiene, or different parenting practices in these groups (Ng, Demopoulos, Mobley, & Ditmyer, 2013). This means that differences between the diagnostic groups is somewhat confounded by ethnicity, but no studies exist to the researcher's knowledge on the relationship between ethnicity and anxiety in children with ASD.

6.1.4 Gender

In the first qualitative study, only mothers of children with ASD took part in the study and none of the fathers, which could be considered a limitation in the study, as it provides the research with only the mothers' perspectives. However, it has been found in previous literature that mothers tend to take part in research studies more than fathers (Fine et al., 2005; Murphy & Tierney, 2006). It is also likely that mothers completed the questionnaires in the third study, though this was unfortunately not recorded.

In terms of the third study, there was a significantly higher number of males with ASD in the sample population than females, and there was a modestly higher number of females than males in the TD sample. These differences were found to be statistically significant in the current study. However, compared with the impact of ethnicity, the role of gender and autism has been widely discussed and rates of diagnosed ASD are consistently higher in males than females (Carrillo-Diaz et al., 2013; Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015). Although unbalanced, the ASD sample here reflects the ASD population in terms of gender.

With regard to gender and anxiety, although some studies have found no statistically significant difference in dental anxiety between boys and girls (Paryab & Hosseinbor, 2013), other studies have found that TD girls are more anxious than boys (Alaki, Alotaibi, Almabadi & Alanquri, 2012). Potentially therefore, it might be expected that the group of participants with ASD would have reduced anxiety levels due to the over-representation of boys. The

finding that individuals with ASD are more dentally anxious than the TD sample confirms the degree to which they are affected by anxiety. Further studies with larger samples could explore this in more detail.

6.2 Study Methodology:

6.2.1 Qualitative Studies:

For the first and second qualitative studies, the method chosen for data collection was the semi-structured interview, which was considered the most appropriate for the aims of the study. However, interviews can only obtain the data that the respondents are willing to say, not necessarily what they actually do or genuinely believe in (Green & Thorogood, 2004).

Given that individuals with ASD are more likely to interpret communication literally (Kirby, Dickie, & Baranek, 2015), they may not have provided further information because it was not directly requested. Therefore, when conducting interviews with adults with ASD, the researcher sometimes had to rephrase the question, or list a number of narratives that resembled the question.

Another limitation that arose during the first qualitative study was that some of the questions required answers from the subject's memory, such as whether there were any previous events that influenced their fear of the dentist. Some participants with ASD found recalling such details and incidents too difficult. This may relate to difficulty with episodic memory impairments, or the ability to recall previous personal experience (Lind, Williams, & Bowler, 2014). Their difficulty may also be related to the fact that individuals with ASD have a pattern in processing perceptual and cognitive stimuli that is described by weak central coherence (Happé & Frith, 2006). Therefore, people with ASD focus on single parts of the environmental stimuli rather than seeing it as whole, which makes it difficult for them to imagine the whole narrative in their mind (Lind et al., 2014).

6.2.2 Quantitative Study:

There were a number of limitations with regard to the study design and methodology. Most of the measures that were used were not developed for children with ASD and few of them had been used with children with ASD before. The researcher was left with little choice, since this topic has not been extensively studied in the literature, but the reliability of the findings are in question, as the measures have not been validated with this group. Some of the factors that were tested had no existing measures, such as the Dental Experience Questionnaire, which was developed by the researcher herself to capture the negative experiences of dental anxiety.

A second problem with the measures is that there is an overlap in items, as they are asking about similar phenomena. For instance, there are overlaps between Spence Children's Anxiety Scale (SCAS) Physical Injury Fear Sub-scale, and the Dental Fear Survey Schedule-Dental Sub-scale (CFSS-DS). Therefore, the correlations could be an artefact of the overlap between the questions.

Finally, the researcher outlined for the third study that questionnaires should be completed by the child and with the help of parent, if needed. However, there is no guarantee that the child did complete these questionnaires him or herself. The alternative, completing the questionnaires with the help of the researcher, would have been prohibitively time consuming, so this was not an option.

6.3 Future Research and Recommendations

Overall, it is considered that the present study successfully measured the research topic, although there are a number of avenues for further and future research. As recognised, there is currently limited literature on the experience of individuals with ASD and, furthermore, recent and reliable research would be welcomed in all the subject fields discussed in the thesis.

Additionally, although there were significant results from the current thesis, the researcher does recommend these studies to be replicated with larger samples. This would help

to avoid the threats to validity and reliability that can arise from the interpretation of limited qualitative data. In addition, the samples should be matched in age, gender and ethnicity, where possible, to rule out any extraneous factors that could affect the results.

As mentioned, the dentists in the second qualitative study pointed out that different strategies were necessary with individuals with ASD, and this was confirmed by the first qualitative study. However, most of the intervention literature focuses on TD children but the needs of individuals with ASD, especially children, are substantially different. Further research could therefore go on to probe further solutions and interventions for the ASD group in particular. It would be useful to consider the numerous aspects of the ASD disability and examine how these come into play in the dental treatment context. There is a wide variety of techniques used by different dentists, so there is significant scope for continuing professional education to help share best practice (Barnes, Bullock, Bailey, Cowpe, & Karaharju-Suvanto, 2013).

This could include further research on fear of the unknown, worries about what others think, as well as sensory sensitivities. Importantly, it will need to distinguish the findings for individuals with differing levels of severity of ASD, since this affects how cooperative the individual will be with a particular intervention. It is also important to separate findings for children and adults with ASD.

Another interesting point of focus is the cognitions of the dentally anxious individuals. This is interesting in the ASD context because of the cognitive impairments that arise from the disability, making it less clear how individuals with ASD perceive dental treatment. It would therefore be interesting to explore further the thoughts and cognitions held by people with ASD, in order to develop a greater understanding of the causes of their dental anxiety.

6.4 Implications for the Future:

It is very pleasing to find that well-known organisations, such as Autism Speaks and the National Autistic Society, now provide information, leaflets and websites that address dental anxiety. Nevertheless, this multi-method thesis has flagged some new findings regarding predictors of dental anxiety. In particular, dental cognitions have been shown to be related to anxiety; this is important because the information leaflets and good practice guides that currently exist do not pay attention to this factor. Similarly, while all the guides stress the need for good preparation, few recognise the need for some children to take multiple tiny steps towards dental procedures. Understanding what predicts dental anxiety in children with ASD will allow dentists and people in the dentistry profession to address the dental fear with more knowledge and confidence about what is causing it. Moreover, it will give children with ASD the opportunity to have better oral health, which is crucial for their general, as well as emotional wellbeing.

Research into ASD is both exciting and demanding and there is so much more to be done to increase awareness of its nature. Therefore, it behoves research communities, whether in the United Kingdom, Saudi Arabia or elsewhere, to continue the search for greater knowledge and understanding of this intriguing condition.

References

Affrunti, N. W. & Woodruff-Borden, J. (2015). Parental Perfectionism and Overcontrol: Examining Mechanisms in the Development of Child Anxiety. *Journal of Abnormal Child Psychology*, *43*(3), 517–529. doi:10.1007/s10802-014-9914-5.

Alaki, S., Alotaibi1, A., Almabadi, E. & Alanquri, E. (2012). Dental anxiety in middle school children and their caregivers: Prevalence and severity. *Journal of Dentistry and Oral Hygiene, 4*(1), 6-11.

Al-Biltagi & Sarhan, E. A. (2016). Anxiety Disorder in Children: Review. *Journal of Paediatric Care Insight, 1(*1), 18-28.

Almansour, M. A., Alateeq, M. A., Alzahrani, M. K., Algeffari, M. A., Alhomaidan, H.T. (2013). Depression and anxiety among parents and caregivers of autistic spectral disorder children. *Neurosciences (Riyadh), 18*(1), 58-63.

Almeida, R. A., Dickinson, J. E., Maybery, M. T., Badcock, J. C., & Badcock, D. R. (2014). Enhanced global integration of closed contours in individuals with high levels of autistic-like traits. *Vision Research*, *103*, 109–115. doi:10.1016/j.visres.2014.08.015.

Al-Namankany, A., De Souza, M., & Ashley, P. (2012). Evidence-based dentistry: analysis of dental anxiety scales for children. *British dental journal*, *212(5*), 219-222. doi:10.1038/sj.bdj.2012.174.

American Psychiatric Association. (1952). *Diagnostic and Statistical Manual of Mental Disorders* (1st Ed.). Washington, DC.

American Psychiatric Association. (1968). *Diagnostic and Statistical Manual of Mental Disorders* (2nd Ed.). Washington, DC.

American Psychiatric Association. (1980). *Diagnostic and Statistical Manual of Mental Disorders* (3rd Ed.). Washington, DC.

American Psychiatric Association. (2013). *Diagnostic and statistical Manual of Mental Disorders (5th ed)*. Washington, DC.

Anderson, C. (2010). Presenting and evaluating qualitative research. *American journal of pharmaceutical education, 74*(8), 1-7.

Appukuttan, D. P., Tadepalli, A., Cholan, P. K., Subramanian, S., Vinayagavel, M. (2013). Prevalence of dental anxiety among patients attending a dental educational institution in Chennai, India--a questionnaire based study. *Oral Health Dental Management, 12*(4), 289-294. doi: 10.4172/2247-2452.1000529.

Armfield, J. M. (2006). Cognitive vulnerability: a model of the etiology of fear. *Clinical Psychology Review, 26*(6), 746-768. doi:10.1016/j.cpr.2006.03.007.

Armfield, J. M. (2010). Towards a better understanding of dental anxiety and fear: cognitions vs. experiences. *European Journal of Oral Sciences, 118*(3), 259-264. doi: 10.1111/j.1600-0722.2010.00740.x.

Armfield, J M. (2013). What goes around comes around: revisiting the hypothesized vicious cycle of dental fear and avoidance. *Community dentistry and oral epidemiology, 41*(3), 279-287. doi:10.1111/cdoe.12005.

Armfield, J.M., & Heaton, L.J. (2013). Management of fear and anxiety in the dental clinic: a review. *Australian Dental Journal, 58*(4), 390-407. doi:10.1111/adj.12118.

Armfield, J. M., Slade, G. D., & Spencer, A. J. (2009). Dental fear and adult oral health in Australia. *Community Dentistry and oral epidemiology*, *37*(3), 220-230. doi:10.1111/j.1600-0528.2009.00468.x.

Asselmann, E. & Beesdo-Baum, K. (2015). Predictors of the course of anxiety disorders in adolescents and young adults. *Current Psychiatry Reports. 17*(2) 543. doi: 10.1007/s11920-014-0543z.

Attride-Stirling, *J.* (2001). *Thematic networks: An analytic tool for qualitative research*. Qualitative Research. 1(3), 385–405. doi: 10.1177/146879410100100307.

Autism Research Institute (2016). *Updates to the APA in DSM-V – What do the Changes Mean to Families Living with Autism?* Retrieved from http://www.autism.com/news_dsmV.

Avcil, S., Baykara, B., Baydur, H.,. Münir, K.M., & Emiroğlu, N. I. (2015). The Validity and Reliability of The Social Communication Questionnaire-Turkish Form in Autistics Aged 4-18 Years**.** *Turkish Journal of Psychiatry, 26*(1), 56–64.doi: 10.5080/u7298.

Avramidis, E., & Smith, B. (1999). An introduction to the major research paradigms and their methodological implications for special needs research. *Emotional and Behavioural Difficulties, 4*(3), 27-36. doi: 10.1080/1363275990040306

Bahammam, M. A. & Hassan, M. H. (2014). Validity and reliability of an Arabic version of the modified dental anxiety scale in Saudi adults. *Saudi Medical Journal,35* (11), 1384-1389.

Barnes, E., Bullock, A, Bailey, S., Cowpe, J., & Karaharju-Suvanto, T. (2013). A review of continuing professional development for dentists in Europe. *European Journal of Dental Education, 17*, 5-17. doi:10.1111/eje.12045.

Barbaresi, W, J., Katusic, S. K., & Voigt, R. G. (2006). Autism: a review of the state of the science for pediatric primary health care clinicians. *Archives of pediatrics & adolescent medicine*, *160*(11), 1167-1175. doi: 10.1001/archpedi.160.11.1167.

Baron-Cohen, S. (2002). The extreme male brain theory of autism. Trends in Cognitive Sciences, 6(6), 248–254. doi:10.1016/S1364-6613(02)01904-6.

Baron-Cohen, S. (2009). Autism: the empathizing–systemizing (E-S) theory. *Annals of the New York Academy of Sciences*, *1156*(1), 68-80. doi: 10.1111/j.1749-6632.2009.04467.x.

Baron-Cohen, S., Leslie, A. M., Frith, U. (1985). Does the autistic child have a "theory of mind"?. Cognition, 21(1), 37-46. doi: 10.1016/0010-0277(85)90022-8.

Bayer, J. K., Sanson, A. V., & Hemphill, S. A. (2006). Parent Influences on Early Childhood Internalizing Difficulties. *Journal of Applied Developmental Psychology*, 27, 542–559. doi:10.1016/j.appdev.2006.08.002.

Beaton, L., Freeman, R., & Humphris, G. (2014). Why are people afraid of the dentist? Observations and explanations. *Medical principles and practice*, *23*(4), 295-301.

Beesdo, K., Knappe, S., & Pine, D. S. (2009). Anxiety and anxiety disorders in children and adolescents: developmental issues and implications for DSM-V. *Psychiatric Clinics of North America*, *32*(3), 483-524. doi:10.1016/j.psc.2009.06.002.

Bellini, S. (2006). The Development of Social Anxiety in Adolescents With Autism Spectrum Disorders. *Focus on Autism & Other Developmental Disabilities, 21*(3), 138-145. doi: 10.1177/10883576060210030201.

Belsky, J. & Pluess, M. (2009). Beyond diathesis stress: Differential susceptibility to environmental influences. *Psychological Bulletin, 135*(6), 885–908. doi:10.1037/a0017376.

Ben-Sasson, A., Hen, L., Fluss, R, Cermak, S.A., Engel-Yeger, B., Gal, E. (2009). A meta-analysis of sensory modulation symptoms in individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders 3*9(1), 1–11. doi: 10.1007/s10803-008-0593-3.

Bettelheim, B. (1967). *The Empty Fortress: Infantile Autism and the Birth of the Self.* New York, NY: The Free Press.

Bilder, D., Botts, E. L., Smith, K. R., Pimentel, R., Farley, M., Viskochil, J., … Coon, H. (2013). Excess Mortality and Causes of Death in Autism Spectrum Disorders: A Follow up of the 1980s Utah/UCLA Autism Epidemiologic Study. *Journal of Autism and Developmental Disorders*, *43*(5), 1196–1204. http://doi.org/10.1007/s10803-012-1664-z.

Blanche, E. I., Parham, D., Chang, M. & Mallinson, T. (2014). Development of an Adult Sensory Processing Scale (ASPS). *The American Journal of Occupational Therapy, 68*(5), 531-538. doi:10.5014/ajot.2014.012484.

Blomqvist, M., Dahllöf, G. & Bejerot, S. (2014). Experiences of Dental Care and Dental Anxiety in Adults with Autism Spectrum Disorder. *Autism Research and Treatment,* 1-8. doi: 10.1155/2014/238764.

Blumberg, S. J., Bramlett, M. D., Kogan, M. D., Schieve, L. A., Jones, J. R., & Lu, M. C. (2013). Changes in prevalence of parent-reported autism spectrum disorder in school-aged US children: 2007 to 2011–2012. *National health statistics reports*, *65*(20), 1-7.

Bögels, S. M., & Brechman-Toussaint, M. L. (2006). Family issues in child anxiety: Attachment, family functioning, parental rearing and beliefs. *Clinical Psychology Review, 26*(7), 834-856. doi: http://dx.doi.org/10.1016/j.cpr.2005.08.001.

Booth, R., & Happe, F. (2010). "Hunting with a knife and...fork": Examining central coherence in autism, attention deficit/hyperactivity disorder, and typical development with a linguistic task. *Journal of Experimental Child Psychology*, *107*, 377–393. doi: 10.1016/j.jecp.2010.06.003.

Boucher, J., Mayes, A., Bigham, S. (2012). Memory in autistic spectrum disorder. *Psychological Bulletin, 138*(3), 458-496. doi: 10.1037/a0026869.

Boulter, C., Freeston, M., South, M., & Rodgers, J. (2014). Intolerance of uncertainty as a framework for understanding anxiety in children and adolescents with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *44*(6), 1391-1402. doi: 10.1007/s10803-013-2001-x.

Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*, 77-101. doi: 10.1191/1478088706qp063oa.

Brennan, C., Worrall-Davies, A., McMillan, D., Gilbody, S., & House, A. (2010). The Hospital Anxiety and Depression Scale: A diagnostic meta-analysis of case-finding ability. *Journal of Psychosomatic Research, 69*, 371-378. doi: 10.1016/ j.jpsychores.2010.04.006.

Brewster, S., & Coleyshaw, L. (2011). Participation or exclusion? Perspectives of pupils with autistic spectrum disorders on their participation in leisure activities. *British Journal of Learning Disabilities, 39*(4), 284-291. doi: 10.1111/j.1468-3156.2010.00665.x

Brooker, R. J., Neiderhiser, J. M., Leve, L. D., Shaw, D. S., Scaramella, L. V., & Reiss, D. (2015). Associations Between Infant Negative Affect and Parent Anxiety Symptoms are Bidirectional: Evidence from Mothers and Fathers. *Frontiers in Psychology*, *6*, 1875. doi:10.3389/fpsyg.2015.01875.

Bryman, A. (2012). *Social Research Methods*: OUP Oxford.

Bultas, M. (2012). The health care experiences of preschool children with autism. *Journal of Pediatric Nursing, 27*(5), 460- 470. doi:10.1016/j.pedn.2011.05.005.

Cagetti, M. G., Mastroberardino, S., Campus, G., Olivari, B., Faggioli, R., Lenti, C., & Strohmenger, L. (2015). Dental care protocol based on visual supports for children with autism spectrum disorders. *Medicina oral, patologia oral y cirugia bucal*, *20*(5), e598-e604. doi: 10.4317/medoral.20424.

Campbell, J. L., Quincy, C., Osserman, J. and Pedersen, O. K. (2013). Coding In-depth Semi structured Interviews: Problems of Unitization and Intercoder Reliability and Agreement. *Sociological Methods & Research, 42*(3), 294-320. doi: 10.1177/0049124113500475.

Catanzaro M. (1988) Using qualitative analytical techniques. In Nursing Research; Theory and Practice (Woods P. & Catanzaro M., eds), C.V. Mosby Company, New York, pp. 437–456.

Carrillo-Diaz, M., Crego, A., Armfield, J. M., & Romero, M. (2012). Self-assessed oral health, cognitive vulnerability and dental anxiety in children: Testing a mediational model. *Community Dentistry and Oral Epidemiology, 40*, 8-16. doi: 10.1111/j.1600-0528.2011.00646.x.

Carrillo-Diaz, M., Crego, A., & Romero-Maroto, M. (2013). The influence of gender on the relationship between dental anxiety and oral health-related emotional well-being. *International Journal of Paediatric Dentistry, 23*, 180-187. doi:10.1111/j.1365-263X.2012.01242.x.

Carrillo-Díaz, M., Crego, A., Armfield, J., & Romero, M. (2013). The moderating role of dental expectancies on the relationship between cognitive vulnerability and dental fear in children and adolescents. *Community dentistry and oral epidemiology, 41*(3), 269-278. doi: 10.1111/cdoe.12009.

Cartwright-Hatton, S., McNicol, K., & Doubleday, E. (2006). Anxiety in a neglected population: Prevalence of anxiety disorders in pre-adolescent children. *Clinical Psychology Review, 26,* 817-833. doi:10.1016/j.cpr.2005.12.002.

Castro, F. G., Kellison, J. G., Boyd, S. J., & Kopak, A. (2010). A Methodology for Conducting Integrative Mixed Methods Research and Data Analyses. *Journal of mixed methods research, 4*(4), 342-360. doi: 10.1177/1558689810382916

Cermak, S. A., Stein Duker, L. I., Williams, M. E., Dawson, M. E., Lane, C. J. & Polido, J. C. (2015). Sensory Adapted Dental Environments to Enhance Oral Care for Children with Autism

Spectrum Disorders: A Randomized Controlled Pilot Study. *Journal of Autism and Developmental Disorders, 45*(9), 2876-2888. doi: 10.1007/s10803-015-2450-5.

Chalfant, A. M. (2011). Managing Anxiety in People with Autism*: A Treatment Guide for Parents, Teachers, and Mental Health Professionals.* (chap. 2.) USA. Woodbine House.

Charman, T., Pickles, A., Simonoff, E., Chandler, S., Loucas, T., & Baird, G. (2011). IQ in children with autism spectrum disorders: data from the Special Needs and Autism Project (SNAP). *Psychological medicine*, *41*(03), 619-627. doi:10.1017/S0033291710000991.

Charnsil, C., Sriapai, P., (2011). Attention deficit hyperactivity symptoms in children with autistic disorder: a cross-sectional descriptive study. *Journal of the medical association of Thailand, 94* (2),231-234.

Cocia, I. R., Uscătescu, L. C., & Rusu, A. S. (2012). Attention Bias to Threat in Anxiety-Prone Individuals. *Journal of Psychophysiology, 26,* 74-82*. doi:* 10.1027/0269-8803/a000069.

Cole, K. L. & Edwards, C. (2015). Sensory Sensitivities of Young Adults with High-Functioning Autism Spectrum Disorders. *Explorations,* 80, 91.

Coric, A., Banozic, A., Klaric, M., Vukojevic, K. Puljak, L. (2014). Dental fear and anxiety in older children: An association with parental dental anxiety and effective pain coping strategies. *Journal of Pain Research, 7*, 515–521. doi: 10.2147/JPR.S67692.

Courtemanche, A. B. & Black, W. R. (2016). Everyday expressions of pain in children with and without autism spectrum disorder. *Research in Autism Spectrum Disorders, 26*, 65–70. doi:10.1016/j.rasd.2016.01.010.

Cowan, N. (2014). Working memory underpins cognitive development, learning, and education. *Educational Psychology Review*, *26*(2), 197-223. doi:10.1007/s10648-013-9246-y.

Craske, M. G., Rauch, S. L., Ursano, R., Prenoveau, J., Pine, D. S., & Zinbarg, R. E. (2009). What is an Anxiety Disorder?, *Depression and Anxiety*, 26, 1066–1085. doi:10.1002/da.20633.

Creswell, J, W. (2009). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. Thousand Oaks, CA: Sage Publications.

Creswell, J. W. & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice, 39 (3)*, 124–130. doi:10.1207/s15430421tip3903_2.

Cresswell, C., Waite, P. & Cooper, P.J. (2014). Assessment and Management of Anxiety Disorders in Children and Adolescents. *Archives of Disease in Childhood*, *99*(7), 674-678. doi:10.1136/archdischild-2013-303768.

Creswell, J, W, & Poth, C, N. (2017). *Qualitative inquiry and research design: Choosing among five approaches*: Sage publications.

Cross-Disorder Group of the Psychiatric Genomics Consortium. (2013). Genetic relationship between five psychiatric disorders estimated from genome-wide SNPs. *Nature Genetics*, *45*(9), 984–994. http://doi.org/10.1038/ng.2711.

Davidov, M., & Grusec J. E. (2006). Untangling the Links of Parental Responsiveness to Distress and Warmth to Child Outcomes. *Child Development*, 77(1), 44–58. doi: 10.1111/j.1467-8624.2006.00855.x.

Davies, E. B & Buchanan, H. (2013). An Exploratory Study Investigating Children's Perceptions of Dental Behavioural Management Techniques. *International Journal of Paediatric Dentistry, 23*(4), 297-309. doi: 10.1111/ipd.12007.

Davis III, Thompson, E., White, S.W., Ollendick, Thomas H., (2014). *Handbook of Autism and Anxiety*. London. Springer.

Daughters, H., Palermo, T., & Koh, J. (2007). Procedural pain and distress in children with autism - A pilot study. *The Journal of Pain, 8*(4), S31. doi: 10.1016/j.jpain.2007.02.124.

Degnan, K. A., Almas, A. N., & Fox, N. A. (2010). Temperament and the environment in the etiology of childhood anxiety. *Journal of Child Psychology and Psychiatry, 51*, 497–515. doi: 10.1111/j.1469-7610.2010.02228.x.

De Bruin, E. I., Ferdinand, R. F., Meesters, S., de Nijs, P. F. & Verheij, F. (2007). High rates of psychiatric co-morbidity in PDD-NOS. *Journal of Autism and Developmental Disorders, 37(5)*, 877–886. doi: 10.1007/s10803-006-0215-x.

De Jongh, A, Adair, P., & Meijerink-Anderson, M. (2005). Clinical management of dental anxiety: What works for whom?. *International Dental Journal, 55*, 73–80. doi: 10.1111/j.1875-595X.2005.tb00037.x.

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

Delli, K., Reichart, P. A., Bornstein, M. M., & Livas, C. (2013). Management of children with autism spectrum disorder in the dental setting: Concerns, behavioural approaches and recommendations. *Medicina Oral, Patologia Oral Y Cirugia Bucal, 18*(6), e862-e868. doi: 10.4317/medoral.19084.

Denscombe, M. (2003). *The Good Research Guide: for small-scale social research projects*. Maidenhead: Open University Press.

Dikshit, P., Limbu, S. & Bhattarai, K. (2013). Evaluation of Dental Anxiety in Parents Accompanying their Children for Dental Treatment. *Orthodontic Journal of Nepal, 3*(1), 47-52. doi: 10.3126/ojn.v3i1.9282.

Donnelly, C. L., & Rhoads, J.C. (2012). *Anxiety Disorders in Childhood and Adolescence:Clinical Child Psychiatry*. 3rd Edition. John Wiley & Sons.

Donvan, J., Zucker, C. (2016). *In a Different Key: The Story of Autism.* Crown/Archetype.

Donovan, M. J. (2010). The Impact of" Hurricane" Hannah: The Government's Decision to Compensate in One Girl's Vaccine Injury Case Could Drastically Alter the Face of Public Health. *Jurimetrics*, 229-259.

Dua R, Jindal R & Saini N. (2016). Autism Speaks, Listen Carefully and Act Accordingly: A Review for Pediatric Dentist. *International Journal of Oral Health and Medical Research, 2*(6), 198-202.

Du, R. Y., Yiu, C. K., King, N. M., Wong, V. C., & McGrath, C. P. (2014). Oral health among preschool children with autism spectrum disorders: A case-control study. *Autism, 19*(6), 746-751. doi:: 10.1177/1362361314553439.

Du, R. Y., Yiu, C. C., Wong, V. C., & McGrath, C. P. (2015). Autism developmental profiles and cooperation with oral health screening. *Journal of Autism and Developmental Disorders*, 45(9), 2758-2763. doi: 10.1007/s10803-015-2416-7.

Dumitrescu, A. L., Kawamura, M., Dogaru, B. C., & Dogaru, C. D. (2010). Relation of achievement motives, satisfaction with life, happiness and oral health in Romanian university students. *Oral health & preventive dentistry*, *8*(1), 15-22.

Elberling, H., Linneberg, A., Rask, C. U., Houman, T., Goodman, R., Mette Skovgaard, A. (2015). Psychiatric disorders in Danish children aged 5-7 years: A general population study of prevalence and risk factors from the Copenhagen Child Cohort (CCC 2000). *Nordic Journal of Psychiatry, 70*(2), 146-55. doi: 10.3109/08039488.2015.1070199.

El-Housseiny, A. A., Alsadat, F. A., Alamoudi, N. M., El Derwi, D. A., Farsi, N. M., Attar, M. H. & Andijani, B. M. (2016). Reliability and validity of the Children's Fear Survey Schedule-Dental Subscale for Arabic-speaking children: A cross-sectional study. *BMC Oral Health, 16*(49), 1-9. doi: 10.1186/s12903-016-0205-0

El-Housseiny, A. A., Merdad, L. A., Alamoudi, N. A. & Farsi, N. M. (2015). Effect of Child and Parent Characteristics on Child Dental Fear Ratings: Analysis of Short and Full Versions of Children's Fear Survey Schedule Dental Subscale. *Oral Health Dental Med, 14*(1), 9 - 16.

Eli, I., Uziel, N., Blumensohn, R., & Baht, R. (2004). Modulation of dental anxiety [mdash] the role of past experiences, psychopathologic traits and individual attachment patterns. *British Dental Journal, 196*(11), 689-694. doi:10.1038/sj.bdj.4811352.

El Khatib, A. A., El Tekeya, M. M., El Tantawi, M. A., & Omar, T. (2014). Oral health status and behaviours of children with Autism Spectrum Disorder: a case–control study. *International Journal of Paediatric Dentistry*, *24*(4), 314-323. doi: 10.1111/ipd.12067.

Ellis, B. J., Boyce, W. T., Belsky, J., Bakermans-Kranenburg, M. J., & van Ijzendoorn, M. H. (2011). Differential susceptibility to the environment: An evolutionary–neurodevelopmental theory. *Development and Psychopathology, 23*(1), 7–28. doi:10.1017/ S095457941000061.

Engel-Yeger, B. (2012). Validating the Adolescent/Adult Sensory Profile and examining its ability to screen sensory processing difficulties among Israeli people. *The British Journal of Occupational Therapy, 75(7)*, 321–329. doi: 10.4276/030802212X13418284515839.

Evans, D., Canavera, K., Kleinpeter, F., Maccubbin, E., & Taga, K. (2005). The Fears, Phobias and Anxieties of Children with Autism Spectrum Disorders and Down Syndrome: Comparisons with Developmentally and Chronologically Age Matched Children. *Child Psychiatry & Human Development, 36*(1), 3-26. doi: 10.1007/s10578-004-3619-x.

Farrugia, S., & Hudson, J. (2006). Anxiety in adolescents with Asperger syndrome: Negative thoughts, behavioral problems, and life interference. *Focus on Autism and Other Developmental Disabilities*, *21*(1), 25-35.doi:10.1177/10883576060210010401.

Fine, S. E., Weissman, A., Gerdes, M., Pinto-Martin, J., Zackai, E. H., McDonald-McGinn, D. M., & Emanuel, B. S. (2005). Autism Spectrum Disorders and Symptoms in Children with Molecularly Confirmed 22q11.2 Deletion Syndrome. *Journal of autism and developmental disorders, 35*(4), 461-470. doi: 10.1007/s10803-005-5036-9.

Folstein, S., & Rutter, M. (1977). Infantile autism: a genetic study of 21 twin pairs. *Journal of Child psychology and Psychiatry*, *18*(4), 297-321. doi: 10.1111/j.1469-7610.1977.tb00443.x.

Folayan, M., Ufomata, D., Adekoya-Sofowora, C., Otuyemi, O., & Idehen, E. (2003). The effect of psychological management on dental anxiety in children. *Journal of Clinical Pediatric Dentistry, 27*(4), 365-370. doi: 10.17796/jcpd.27.4.m97882243p3474hn.

Freeman, M., de Marrais, K., Preissle, J., Roulston, K. & St. Pierre, E. (2007). Standards of Evidence in Qualitative Research: An Incitement to Discourse. *Educational Researcher, 36*, 1–8. doi: 10.3102/0013189X06298009.

Freeman, H. S., & Newland, L. A (2002). Family Transitions During the Adolescent Transition: Implications for Parenting. *Adolescence*, 37, 457–475.

Frith, U. (2004). Emanuel Miller lecture: confusion and controversies about Asperger syndrome. *Journal of Child Psychology and Psychiatry, 45*, 672-686. doi: 10.1111/j.1469-7610.2004.00262.x.

Gadow, K. D., DeVincent, C. J., & Drabick, D. A. (2008). Oppositional Defiant Disorder as a Clinical Phenotype in Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 38, 1302-1310. doi: 10.1007/s10803-007-0516-8.

Gaigg, S. B. (2012). The Interplay between Emotion and Cognition in Autism Spectrum Disorder: Implications for Developmental Theory. *Frontiers in Integrative Neuroscience*, *6*, 113. http://doi.org/10.3389/fnint.2012.00113

Garber, J. & Weersing, V. R. (2010). Comorbidity of Anxiety and Depression in Youth: Implications for Treatment and Prevention. *Clinical Psychology : A Publication of the Division of Clinical Psychology of the American Psychological Association*, *17*(4), 293-306. doi: 10.1111/j.1468-2850.2010.01221.x.

Gilbert, N. (2008). *Researching social life*. London: Sage Publications Ltd.

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *British Dental Journal, 204*(6), 291-295.

Gillberg, C., Billstedt, E., Sundh, V., & Gillberg, IC. (2010) Mortality in Autism: A Prospective Longitudinal Community-Based Study. *Journal of Autism and Developmental Disorders*, *40*(3), 352-357. doi: 10.1007/s10803-009-0883-4.

Gisler, V., Bassetti, R., Mericske-Stern, R., Bayer, S., & Enkling, N. (2012). A cross-sectional analysis of the prevalence of dental anxiety and its relation to the oral health-related quality of life in patients with dental treatment needs at a university clinic in Switzerland. *Gerodontology, 29*(2), e290-e296. doi: 10.1111/j.1741-2358.2011.00465.x.

Gandhi, R. P. & Klein, U. (2014). Autism Spectrum Disorders: An Update on Oral Health Management. Journal of *Evidence Based Dental Practice, 14*, 115-126. doi: 10.1016/j.jebdp.2014.03.002.

Geschwind, D. H., & State, M. W. (2015). Gene hunting in autism spectrum disorder: on the path to precision medicine. *The Lancet Neurology*, *14*(11), 1109-1120. doi:10.1016/S1474-4422(15)00044-7.

Godlee, F., Smith, J., & Marcovitch, H. (2011). Wakefield's article linking MMR vaccine and autism was fraudulent. *BMJ*, *342*...doi.org/10.1136/bmj.c7452.

Goldman, S. (2013). Opinion: Sex, Gender and the Diagnosis of Autism — A Biosocial View of the Male Preponderance. *Research in Autism Spectrum Disorders, 7*(6), 675–679. doi:10.1016/j.rasd.2013.02.006.

Goettems, M., L., Ardenghi, T. M., Romano, A. R., Demarco, F., & Torriani, D. D. (2011). Influence of maternal dental anxiety on oral health-related quality of life of preschool children. *Quality of Life Research, 20*, 951-959. doi: 10.1007/s11136-010-9816-0.

Goldin, R. L., Tureck, K., Matson, J. L., Cervantes, P.E., & Jang, J. (2013). A Comparison of Tantrum Behavior Profiles in Children with ASD, ADHD, and Comorbid ASD and ADHD. *Research in Developmental Disabilities*, *34*, 2669-2675. doi: 10.1016/j.ridd.2013.04.022

Gomot, M. & Wicker, B. (2012). A challenging, unpredictable world for people with Autism Spectrum Disorder, *International Journal of Psychophysiology*, 83(2) 240–247. doi: 10.1016/j.ijpsycho.2011.09.01.

Gotham, K., Bishop, S. L., Hus, V., Huerta, M., Lund, S., Buja, A., … Lord, C. (2013). Exploring the Relationship Between Anxiety and Insistence on Sameness in Autism Spectrum Disorders. Autism Research , *Official Journal of the International Society for Autism Research*, *6*, 33–41. Doi:10.1002/aur.1263

Graham, R. A. & Weems, C. F. (2015). Identifying Moderators of the Link Between Parent and Child Anxiety Sensitivity: The Roles of Gender, Positive Parenting, and Corporal Punishment. *Journal of Abnormal Child Psychology, 43*(5), 885–893. doi: 10.1007/s10802-014-9945-y.

Greco, L.A. & Morris, T.L. (2002). Paternal child-rearing style and child social anxiety: investigation of child perceptions and actual father behavior. *Journal of. Psychopathoogy and Behavioral. Assessessment, 24*(4), 259–267. doi: 10.1023/A:1020779000183.

Grimmer, J., King, G. & Superti, C. (2015). The Unreliability of Measures of Intercoder Reliability, and What to do about it. *International Journal of Artificial Intelligence in Education*, *12*, 8–22.

Goldstein, T. R., & Winner, E. (2012). Enhancing empathy and theory of mind. *Journal of Cognition and Development, 13*(1), 19–37. doi:10.1080/15248372.2011.573514.

Gomot, M. & Wicker, B. (2012). A challenging, unpredictable world for people with Autism Spectrum Disorder*., International Journal of Psychophysiology, 83*(2), 240–247. doi: 10.1016/j.ijpsycho.2011.09.01.

Green, J. & Thorogood, N. (2004). *Qualitative methods for health research*. London: Sage Publications.

Grondhuis, S. N. & Aman, M. G. (2012). Assessment of anxiety in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6*, 1345–1365.

Grove, R., Baillie, A., Allison, C. & Baron-Cohen, S. (2013). Empathizing, Systemizing, and Autistic Traits: Latent Structure in Individuals with Autism, Their Parents, and General Population Controls. *Journal of Abnormal Psychology, 122*(2), 600–609.

Gupta, A., Marya, C. M., Bhatia, H. P. and Dahiya, V. (2014). Behaviour management of an anxious child. *Stomatologija, Baltic Dental and Maxillofacial Journal, 16*, 3-6.

Gustafsson, A., Arnrup, K., Broberg, A. G., Bodin, L. & Berggren, U. (2010). Child dental fear as measured with the Dental Subscale of the Children's Fear Survey Schedule: the impact of referral status and type of informant (child versus parent). *Community Dentistry and Oral Epidemiology, 38*, 256-66. doi: 10.1111/j.1600-0528.2009.00521.x.

Guttmann-Steinmetz, S., Gadow, K. D., DeVincent, C. J. & Crowell, J. (2010). Anxiety symptoms in boys with autism spectrum disorder, attention-deficit hyperactivity disorder, or chronic multiple tic disorder and community controls. *Journal of Autism and Developmental Disorders, 40*(8), 1006–1016. doi: 10.1007/s10803-010-0950-x.

Hadad, B. S., & Ziv, Y. (2015). Strong bias towards analytic perception in ASD does not necessarily come at the price of impaired integration skills. *Journal of autism and developmental disorders*, *45*(6), 1499-1512.doi:10.1007/s10803-014-2293-5.

Hahn, E. & Bentley. B. M. (2015). Executive Functions in Children with ASDs. Autism Consortium. 9 Dec. 2013. Retrieved from: http://www.autismconsortium.org/blog/detail/executive-functions-in-children-with-asds>.

Hallett, V., Lecavalier, L., Sukhodolsky, D. G., Cipriano, N., Aman, M. G., McCracken, J. T., ... & Sikich, L. (2013). Exploring the Manifestations of Anxiety in Children with Autism Spectrum Disorders. *Journal of Autism Developmental Disorders, 43*(10), 2341-52. doi:10.1007/s10803-013-1775-1.

Hallmayer, J., Cleveland, S., Torres, A., Phillips, J., Cohen, B., Torigoe, T., ... & Lotspeich, L. (2011). Genetic heritability and shared environmental factors among twin pairs with autism. *Archives of general psychiatry*, *68*(11), 1095-1102.

Happé, F., & Frith, U. (2006). The weak coherence account: Detail-focused cognitive style in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 36*(1), 5-25. doi: 10.1007/s10803-005-0039-0.

Hastings, R. P., & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation, 107*(3), 222-232. doi: 10.1352/0895-8017(2002)107<0222:BPOCWA>2.0.CO;2.

Harrington, C., Foster, M., Rodger, S., & Ashburner, J. (2014). Engaging young people with Autism Spectrum Disorder in research interviews. British Journal of Learning Disabilities, 42(2), 153-161. doi: 10.1111/bld.12037.

Healy, S., Msetfi, R., & Gallagher, S. (2013). 'Happy and a bit Nervous': the experiences of children with autism in physical education. British Journal of Learning Disabilities, 41(3), 222-228. doi: 10.1111/bld.12053.

Hernandez, P., & Ikkanda, Z. (2011). Applied behavior analysis: Behavior management of children with autism spectrum disorders in dental environments. *Journal of the American Dental Association, 142*(3), 281-287.

Hill, E. L. (2004). Executive dysfunction in autism. *Trends in Cognitive Science, 8*(1), 26-32.doi: 10.1016/j.tics.2003.11.003.

Hilton, C. L., Harper, J. D., Kueker, R. H., Lang, A. R., Abbacchi, A. M., Todorov, A., & LaVesser, P. D. (2010). Sensory responsiveness as a predictor of social severity in children with high

functioning autism spectrum disorders. *Journal of Autism and Developmental Disorders, 40 (8)*, 937–945. doi: 10.1007/s10803-010-0944-8.

Hinshaw, S. P. (2008). Developmental Psychopathology as a Scientific Discipline: Relevance to Behavioral and Emotional Disorders of Childhood and Adolescence. In Beauchaine T.P., Hinshaw, S.P. (Eds.): *Child and adolescent psychopathology* (pp. 3–26). Hoboken, New Jersey. John Wiley & Sons.

Hollocks, M. J., Ozsivadjian, A., Matthews, C. E., Howlin, P., Simonoff, E. (2013). The relationship between attentional bias and anxiety in children and adolescents with autism spectrum disorders. *Autism Reseacrh, 6*(4), 237-247. doi: 10.1002/aur.1285.

Holloway, I., & Fullbrook, P. (2001) Revisiting qualitative inquiry: Interviewing in nursing and midwifery research. *Journal of research in nursing, 6*, 539-550. doi: 10.1177/136140960100600111.

Hood, H. K. & Antony, M. M. (2012). Evidence-based assessment and treatment of specific phobias in adults. In E. D. Thompson,, T. H. Ollendick & L. Öst, (Eds.) *Intensive One-Session Treatment of Specific Phobias.* (pp. 19-42) New York, NY: Springer.

Howitt, D. (2010). *Introduction to Qualitative methods in psychology*. London, England: Pearson.

Howlin, P. (2004). *Autism and Asperger's Syndrome: Preparing for Adulthood*. 2nded London: Routledge.

Hudson, J. L., Lester, K. J., Lewis, C. M., Tropeano, M., Creswell, C., Collier, D. A., ... & Roberts, S. (2013). Predicting outcomes following cognitive behaviour therapy in child anxiety disorders: the influence of genetic, demographic and clinical information. *Journal of Child Psychology and Psychiatry*, *54*(10), 1086-1094. doi: 10.1111/jcpp.12092.

Humphris, G., Crawford, J. R., Hill, K., Gilbert, A. & Freeman, R. (2013). UK population norms for the modified dental anxiety scale with percentile calculator: adult dental health survey 2009 results. *BMC Oral Health, 13*, 29. doi: 10.1186/1472-6831-13-29.

Humphris, G. & Hull, P. (2007). Do dental anxiety questionnaires raise anxiety in dentally anxious adult patients? A two wave panel study. *Primary Dental Care, 14*(1), 7–11. doi: 10.1308/135576107779398165.

Humphris, G., & King, K. (2011). The prevalence of dental anxiety across previous distressing experiences. *Journal of Anxiety Disorders, 25*, 232-236. doi: 10.1016/j.janxdis.2010.09.007

Humphris, G. M., Spyt, J., Herbison, A., & Kelsey, T. (2016). Adult dental anxiety: Recent assessment approaches and psychological management in a dental practice setting. *Dental Update, 43,* 388-394.

Hunt-Shanks, T., Blanchard, C., Reid, R., Fortier, M. & Cappelli, M. (2010). A psychometric evaluation of the Hospital Anxiety and Depression Scale in cardiac patients: addressing factor structure and gender invariance. *British Journal of Health Psychology, 15*(1), 97–114. doi: 0.1348/135910709X432745.

Isong, I. A., Rao, S. R., Holifield, C., Iannuzzi, D., Hanson, E., Ware, J., & Nelson, L. P. (2014). Addressing dental fear in children with autism spectrum disorders a randomized controlled pilot study using electronic screen media. *Clinical Pediatrics*,.doi: 10.1177/0009922813517169.

Iwata, B. & Dozier, C. L. (2008) Clinical application of functional analysis methodology. *Behavior Analysis Practice, 1*(1), 3-9.

Jaber, M. A. (2011). Dental caries experience, oral health status and treatment needs of dental patients with autism. *Journal of Applied Oral Science*, *19*(3), 212-217. doi:10.1590/S1678-77572011000300006.

Jennett, H., Vasa, R. A., & Hagopian, L. (2013). Anxiety in children with autism spectrum disorder. In *Pediatric Anxiety Disorders* (pp. 345-377). New York: Springer.

Johnson, N. & Rodriguez, D. (2013). Children With Autism Spectrum Disorder at a Pediatric Hospital: A Systematic Review of the Literature. *Pediatric Nursing*, *39*(3), 131-41.

Jones, E. J. H., Webb, S. J., Estes, A., & Dawson, G. (2013). Rule learning in autism: The role of reward type and social context. *Developmental Neuropsychology, 38*, 58– 77. doi:10.1080/87565641.2012.727049.

Jovanovic, T., Nylocks, K. M., Gamwell, K. L., Smith, A., Davis, T. A., Norrholm, S. D. & Bradley, B. (2014). Development of fear acquisition and extinction in children: Effects of age and anxiety. *Neurobiol Learn Mem, 113*, 135–142. doi: 10.1016/j.nlm.2013.10.016.

Jutte, J. E., Needham, D. M., Pfoh E. R. & Bienvenu, OJ. (2015). Psychometric evaluation of the Hospital Anxiety and Depression Scale 3 months after acute lung injury. *Journal of Critical Care, 30(*4), 793-798. doi: 10.1016/j.jcrc.2015.04.006.

Kagan, J. (1978). The parental love trap. *Psychology Today, 12*, 54-61

Kanner, L. (1943). Autistic Disturbances of Affective Contact. *Nervous Child*, *2*, 217-250.

Kendall, P. C., Compton, S. N., Walkup, J. T., Birmaher, B., Albano, A. M., Sherrill, J., … Piacentini, J. (2010). Clinical characteristics of anxiety disordered youth. *Journal of Anxiety Disorders*, *24*(3), 360–365. http://doi.org/10.1016/j.janxdis.2010.01.009.

Kern, J. K., Garver, C. R., Carmody, T., Andrews, A. A., Trivedi, M. H., & Mehta, J. A. (2007). Examining Sensory Quadrants in Autism. *Research in Autism Spectrum Disorders, 1* (2), 185-193. doi: 10.1016/j.rasd.2006.09.002

Keehn, B., Brenner, L. A., Ramos, A. I., Lincoln, A. J., Marshall, S. P., & Muller, R. *(2009).* Eye-movement patterns during an embedded figures test in children with ASD. *Journal of Autism and Developmental Disorders, 39*, 383–387. doi:10.1007/s10803-008-0608-0.

Kim, Y. S., Fombonne, E., Koh, Y. J., Kim, S. J., Cheon, K. A., & Leventhal, B. L. (2014). A comparison of DSM-IV pervasive developmental disorder and DSM-5 autism spectrum disorder prevalence in an epidemiologic sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, *53*(5), 500-508.

Kim, Y. S. & Leventhal, B. L. (2015). Genetic Epidemiology and Insights into Interactive Genetic and Environmental Effects in Autism Spectrum Disorders. *Biol Psychiatry, 77*(1) 66–74. doi: 10.1016/j.biopsych.2014.11.001.

Kim, A., Shim,Y., Park, S., Kim, H. & An, S. (2015). Reliability and validity of the Korean version of the Dental Fear Survey. *Journal of Dental Anesthesia and Pain Medicine, 15*(2), 85-92. doi: 10.17245/jdapm.2015.15.2.85.

King, B. N., Hampton, L.P. & Strommen, M. A., Fraser, L.P. (2014). Anxiety Symptoms in Children and Adolescents: A Focus on Special Populations. Minnesota Association for Children's Mental Health (ACMH).

Kirby, A. V., Dickie, V. A., & Baranek, G. T. (2015). Sensory experiences of children with autism spectrum disorder: In their own words. *Autism, 19*(3) 316–326. doi: 10.1177/1362361314520756.

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

Klin, A., Pauls, D., Schultz, R., & Volkmar, F. (2005). Three diagnostic approaches to Asperger syndrome: implications for research. *Journal of autism and developmental disorders*, *35*(2), 221-234. doi:10.1007/s10803-004-2001-y.

Klingberg, G., & Broberg, A. G. (2007). Dental fear/anxiety and dental behaviour management problems in children and adolescents: a review of prevalence and concomitant psychological factors. *International Journal of Paediatric Dentistry, 17*(6), 391-406. doi: 10.1111/j.1365-263X.2007.00872.x.

Koldewyn, K., Jiang, Y. V., Weigelt, S. & Kanwisher, N. (2013). Global/local processing in autism: Not a disability, but a disinclination. *Journal of Autism and Developmental Disorders, 43*(10), 2329–2340. doi:10.1007/s10803-013-1777-z.

Kohane, I. S., McMurry, A., Weber, G., MacFadden, D., Rappaport, L., Kunkel, L., ... & Churchill, S. (2012). The co-morbidity burden of children and young adults with autism spectrum disorders. *PloS one*, *7*(4), e33224. Doi:10.1371/journal.pone.0033224.

Kramer, P. F., Ardenghi, T. M., Ferreira, S., Fischer, A., Cardoso, L., Feldens, C. A. (2008). Use of dental services by preschool children in Canela, Rio Grande do Sul State, Brazil.*Cadernos de Saude Publica, 24*(1), 150-156. doi:10.1590/S0102-311X2008000100015.

Kreslins, A., Robertson, A., & Melville, C. (2015). The effectiveness of psychosocial interventions for anxiety in children and adolescents with autism spectrum disorder: a systematic review and meta-analysis. *Child and adolescent psychiatry and mental health, 9* , 22. doi: 10.1186/s13034-015-0054-7.

Krikken, J.B., Ten Cate, J.M. & Veerkamp, J.S. (2010). Child dental fear and general emotional problems: a pilot study. *European Archives of Paediatric Dentistry. 11*(6), 283–286.

Krikken, J.B., van Wijk, A.J., ten Cate, J. M. & Veerkamp, J. S. (2013). Measuring dental fear using the CFSS-DS. Do children and parents agree?. *International Journal of Paediatric Dentistry, 23*(2), 94-100. doi: 10.1111/j.1365-263X.2012.01228.x.

Krippendorff, K. (2011). Agreement and Information in the Reliability of Coding. *Communication Methods and Measures, 5*(2), 1-20. doi: 10.1080/19312458.2011.568376.

Kroniņa, L., Stradins, R. & Care, R. (2014). Reliability and Validity of Children's Fear Survey Schedule–Dental Subscale (CFSS-DS) Latvian Version. *Baltic Journal of Psychology, 15*(1, 2), 64–72.

Kroncke, A. P., Willard, M., Huckabee, H. (2016). Assessment of Autism Spectrum Disorder: *Critical Issues in Clinical, Forensic and School Settings. New-York,* USA. Springer.

Kuhaneck, H. M. & Chisholm, E. C. (2012). Improving Dental Visits for Individuals with Autism Spectrum Disorders through an Understanding of Sensory Processing. *Special Care in Dentistry, 32* (6), 229-233. doi: 10.1111/j.1754-4505.2012.00283.x.

Lai, M., Lombardo, M. V., Auyeung, B., Chakrabarti, B. & Baron-Cohen, S. (2015). Sex/Gender Differences and Autism: Setting the Scene for Future Research. Journal of the American Academy of Child & Adolescent Psychiatry, 54(1), 11 -24. doi: 10.1016/j.jaac.2014.10.003.

Lai, B., Milano, M., Roberts, M. W., & Hooper, S. R. (2012). Unmet dental needs and barriers to dental care among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(7), 1294-1303. doi: 10.1007/s10803-011-1362-2.

Lansford, J. E. & Bornstein, M. H.. (2011). Parenting attributions and attitudes in diverse cultural contexts: Introduction to the Special Issue. *Parenting: Science and Practice, 11*, 87–101. doi: 10.1080/15295192.2011.585552.

Lansford, J. E. & Deater-Deckard, K. (2012). Childrearing discipline and violence in developing countries. *Child Development, 83*(1), 62-75. doi: 10.1111/j.1467-8624.2011.01676.x.

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

Lavigne, J. V., Hopkins, J., Gouze, K. R., & Bryant, F. B. (2014). Bidirectional influences of anxiety and depression in young children. *Journal of Abnormal Child Psychology, 4*3(1), 163–176. doi:10.1007/s10802-014-9884-7.

Lazarus, R. S., Dodd, H. F., Majdandžić, M., de Vente, W., Morris, T., Byrow, Y., ... & Hudson, J. L. (2016). The relationship between challenging parenting behaviour and childhood anxiety disorders. *Journal of Affective Disorders, 190*, 784–791. doi: 10.1016/j.jad.2015.11.032.

Lever, A.G., Werkle-Bergner, M., Brandmaier, A.M., Ridderinkhof, K.R., & Geurts, H.M. (2015). Atypical working memory decline across the adult lifespan in autism spectrum disorder?. *Journal of Abnormal Psychology, 124*(4), 1014-1026. doi:10.1037/abn0000108.

Leyfer, O., Folstein, S., Bacalman, S.,Davis, N., Dinh, E., Morgn, J.,...Lainhart, J.,(2006). Comorbid Psychiatric Disorders in Children with Autism: Interview Development and Rates of Disorders. *The journal of autism and developmental disorders, 36*, 849-861. doi 10.1007/s10803-006-0123-0.

Limeres-Posse, J., Castaño-Novoa, P., Abeleira-Pazos, M. & Ramos-Barbosa, I. (2014). Behavioural aspects of patients with Autism Spectrum Disorders (ASD) that affect their dental management. *Medicina Oral Patologia Oral y Cirugia Bucal. 19*(5), e467–e472. doi: 10.4317/medoral.19566.

Lin, C., & Lee, S. (2007). Dental Anxiety and Expectation of Pain: Cognitive Modulation of the Pain Experience of Dental Patients. *Journal of Dental Sciences, 2*(3), 129-135.

Lind, S. E., Williams, D. M., Bowler, D. M. & Peel, A. (2014). Episodic Memory and Episodic Future Thinking Impairments in High-Functioning Autism Spectrum Disorder: An Underlying

Difficulty With Scene Construction or Self-Projection?. *Neuropsychology, 28*(1) 55– 67. doi: 10.1037/neu0000005.

Lisowska, P. & Zoitopoulos, L. (2009). Cognitive behavioural therapy and severe needle phobia – a case study. *Journal of Disability and Oral Health, 10*(3), 135-138.

Ljaljević, A., Matijević, S., Terzić, N., Anđelić, J., & Mugoša, B. (2012). Significance of proper oral hygiene for health condition of mouth and teeth. *Vojnosanitetski pregled*, *69*(1), 16-21.

Loo, C., Graham, R., & Hughes, C. (2009). Behaviour guidance in dental treatment of patients with autism spectrum disorder. *International Journal of Pediatric Dentistry, 19*(6), 390-398. doi: 10.1111/j.1365-263X.2009.01011.x.

Loyd, D. (2013). Obtaining consent from young people with autism to participate in research. *British Journal of Learning Disabilities, 41*(2), 133-140. doi: 10.1111/j.1468-3156.2012.00734.x

Lu, Y., Wei, I. & Huang, C. (2013). Dental health - a challenging problem for a patient with autism spectrum disorder. *General Hospital Psychiatry. 35*(2), 214.e1–214.e3 doi: 10.1016/j.genhosppsych.2012.06.012.

Lugnegard, T., Hallerback, M. U. & Gillberg, C. (2011). Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. *Research in Developmental Disabilties, 32*, 1910-1917. doi: 10.1016/j.ridd.2011.03.025.

Lundström, S., Reichenberg, A., Melke, J., Råstam, M., Kerekes, N., Lichtenstein, P.,…. Anckarsäter, H. (2015), Autism spectrum disorders and coexisting disorders in a nationwide Swedish twin study. *The Journal of Child Psychology and Psychiatry, 56*(6), 702–710. doi:10.1111/jcpp.12329.

Lyall, K., Schmidt, R. J., & Hertz-Picciotto, I. (2014). Environmental Factors in the Preconception and Prenatal Periods in Relation to Risk for ASD. *Handbook of Autism and Pervasive Developmental Disorders, Fourth Edition*.

MacNeil, B.M., Lopes, V.A. & Minnes, P.M. (2009). Anxiety in Children and Adolescents with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 3, 1–21.

Magiati, I., Chan, J., Tan, W., & Poon, K. (2014). Do non-referred young people with Autism Spectrum Disorders and their caregivers agree when reporting anxiety symptoms? A preliminary investigation using the Spence Children's Anxiety Scale. *Research in Autism Spectrum Disorders, 8*(5), 546–558. doi: 10.1016/j.rasd.2014.01.015.

Marshall C. & Rossman G.B. (1995) Designing Qualitative Research. Sage Publications, London.

Marshall, J., Sheller, B. & Mancl, L. (2010). Caries-risk assessment and caries status of children with autism. *Pediatric Dentistry, 32*(1), 69-75.

Marshman, Z., Morgan, A., Porritt, J., Gupta, E., Baker, S., Creswell, C., … & Rodd, H. (2016). Protocol for a feasibility study of a self-help cognitive behavioural therapy resource for the reduction of dental anxiety in young people. *Pilot and Feasibility Studies, 2*, 13. doi: 10.1186/s40814-016-0054-2.

Matson, J. L., Tureck, K., Turygin, N., Beighley, J., & Rieske, R. (2012). Trends and topics in early intensive behavioral interventions for toddlers with autism. *Research in Autism Spectrum Disorders*, *6*(4), 1412-1417.

Matson, J. L. & Sturmey, P. (2011). *International Handbook of Autism and Pervasive Developmental Disorders.* Science & Business Media. Louisiana. Springer.

Mattanah, J.F. (2001). Parental Psychological Autonomy and Children's Academic Competence and Behavioral Adjustment in Late Childhood: More than just Limit-Setting and Warmth. *Merrill-Palmer Quarterly*, 47, 355–376.

May, T, Cornish, K, & Rinehart, NJ. (2015). Parent-Child Agreement Using the Spence Children's Anxiety Scale and a Thermometer in Children with Autism Spectrum Disorder. *Autism research and treatment, 2015*. doi:10.1155/2015/315495.

Mayes, S. D., Calhoun, S. L., Aggarwal, R., Baker, C., Mathapati, S., Molitoris, S., & Mayes, R. D. (2013). Unusual fears in children with autism. *Research in Autism Spectrum Disorders*, *7*(1), 151-158.

Mazefsky, C. A., Goin-Kochel, R. P., Riley, B. P. & Maes, H. H. (2008). Genetic and environmental influences on symptom domains in twins and siblings with autism. *Research in Autism Spectrum Disorders, 2 (2)*, 320–331. doi: 10.1016/j.rasd.2007.08.002.

Mazurek, M. O., Vasa, R. A., Kalb, L. G., Kanne, S.M., Rosenberg, D., Keefer, A.,. & Lowery, L. A. (2012). Anxiety, sensory over-responsivity, and gastrointestinal problems in children with autism spectrum disorders. *Journal of Abnormal Child Psychology, 41(1)*, 165–176. doi: 10.1007/s10802-012-9668-x.

Mazza, M., Pino, M. C., Mariano, M., Tempesta, D., Ferrara, M., De Berardis, D., ... & Valenti, M. (2014). Affective and cognitive empathy in adolescents with autism spectrum disorder. *Frontiers in human neuroscience*, *8*, 791. doi: 10.3389/fnhum.2014.00791.

McAdams, T. A., Rijsdijk, F. V., Neiderhiser, J. M., Narusyte, J., Shaw, D. S., Natsuaki, M. N., ... & Lichtenstein, P. (2015). The relationship between parental depressive symptoms and offspring psychopathology: evidence from a children-of-twins study and an adoption study. Psychological Medicine, 45(12), 2583-2594. doi.org/10.1017/S0033291715000501.

McDonald, J.H. 2014. *Handbook of Biological Statistics* (3rd ed.). Sparky House Publishing, Baltimore, Maryland.

McHugh, R. K., & Otto, M. W. (2011). Domain-general and domain-specific strategies for the assessment of distress intolerance. *Psychology of Addictive Behaviors, 25*(4), 745–749. doi: 10.1037/a0025094.

McHugh, R. K., & Otto, M. W. (2012). Profiles of distress intolerance in a substance dependent sample. *American Journal of Drug and Alcohol Abuse, 38*, 161–165. doi: 10.3109/00952990.2011.643990.

McKenna, P. E., Glass, A., Rajendran, G. & Corley, M. (2015). Strange Words: Autistic Traits and the Processing of Non-Literal Language. *Journal of Autism and Developmental Disorders, 45*(11), 3606–3612. doi: 10.1007/s10803-015-2508-4.

McKinney, C. M., Nelson, T., Scott, J. M., Heaton, L. J., Vaughn, M. G., & Lewis, C. W. (2014). Predictors of unmet dental need in children with autism spectrum disorder: Results from a national sample. *Academic Pediatrics, 14*(6), 624-631. doi: 10.1016/j.acap.2014.06.023.

McLeod, B. D., Wood, J. J., & Weisz, J. R. (2007). Examining the association between parenting and childhood anxiety: A meta-analysis. *Clinical Psychology Review, 27*, 155-172. doi.org/10.1016/j.cpr.2006.09.002.

McPartland, J. C., Reichow, B., & Volkmar, F. R. (2012). Sensitivity and specificity of proposed DSM-5 diagnostic criteria for autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry,* 51(4), 368-383. doi: 10.1016/j.jaac.2012.01.007.

Mendoza-Mendoza, A., Perea, M.B., Yañez-Vico, R. M. & Iglesias-Linares A. (2015). Dental fear in children: The role of previous negative dental experiences. *Clinical Oral Investigation, 19,* 745-51. doi: 10.1007/s00784-014-1380-5.

Mills, I., Frost, J., Cooper, C., Moles, D. R., & Kay, E. (2014). Patient-centred care in general dental practice-a systematic review of the literature. *BMC oral health, 14*, 64.doi: 10.1186/1472-6831-14-64

Milne, E. & Szczerbinski, M. (2009). Global and local perceptual style, field-independence, and central coherence. An attempt at concept validation. *Advances in Cognitive Psychology, 5*, 1–26. doi:10.2478/v10053-008-0062-8.

Mobini, S., & Grant, A. (2007). Clinical Implications of Attentional Bias in Anxiety Disorders. An integrative Literature Review. *Psychotherapy: Theory, Research, Practice, Training, 44*(4), 450-462.

Moosavi, H., Narimani, S. & Vosugh, I. (2015). Study the effects of communication skills training on satisfaction and anxiety level of dentistry students and their patients. *Journal of Dentistry and Oral Care Medicine, 1*(3), 304. doi: 10.15744/2454-3276.1.304.

Moraine, P. (2015). *Autism and Everyday Executive Function: A Strengths-Based Approach for Improving Attention, Memory, Organization and Flexibility*. London, UK; Jessica Kingsley Publishers.

Möricke, E. Buitelaar, J. K. and Rommelse N. N. (2016). Do We Need Multiple Informants When Assessing Autistic Traits? The Degree of Report Bias on Offspring, Self, and Spouse Ratings. *Journal of Autism and Developmental Disorders ,46*, 164–175. doi: 10.1007/s10803-015-2562-y.

Mottron, L., Dawson, M., Soulieres, I., Hubert, B., & Burack, J. A. (2006). Enhanced perceptual functioning in autism: An update, and eight principles of autistic perception. *Journal of Autism and Developmental Disorders, 36*(1), 27–43. doi:10.1007/s10803- 005-0040-7.

Muris, P., (2003). Information Processing Abnormalities in Childhood Anxiety. *Behaviour Change, 20*(3), 129-130. doi.org/10.1375/bech.20.3.129.24834.

Muris, P., & Field, A. P. (2010). The Role of Verbal Threat Information in the Development of Childhood Fear. "Beware the Jabberwock!" *Clinical Child and Family Psychology Review*, *13*(2), 129–150. doi:10.1007/s10567-010-0064-1.

Murphy, T., & Tierney, K. (2006). Parents of Children with Autistic Spectrum Disorders (ASD): A Survey of Information needs. *National Council for Special Education Special Education Research Initiative*.

Nagaraj, A., Ganta, S., Yousuf, A., & Pareek, S. (2014). Enculturation, Myths and Misconceptions Regarding Oral Health Care Practices among Rural Female Folk of Rajasthan. *Ethno Medicine, 8 (2)*, 157-164.

Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, Je. (2009). Qualitative description–the poor cousin of health research? *BMC Medical Research Methodology, 9*(1), 52- 57. doi: 10.1186/1471-2288-9-52

Nelson, T. M., Sheller, B., Friedman, C. S., & Bernier, R. (2014). Educational and therapeutic behavioral approaches to providing dental care for patients with Autism Spectrum Disorder. *Special Care in Dentistry, 35*(3), 105-113. doi: 10.1111/scd.12101.

Ng, S., Demopoulos, C., Mobley, C. & Ditmyer, M. (2013). Parenting style and oral health status. *Open Journal of Pediatrics, 3*, 188-194. doi:10.4236/ojped.2013.33033.

Nicolas, E., Bessadet, M., Collado, V., Carrasco, P., Rogerleroi, V., Hennequin, M. (2010). Factors affecting dental fear in French children aged 5–12 years. *International Journal of Pediatric Dentistry, 20*(5), 366–73.

Nigam, A. G., Marwah, N., Goenka, P., & Chaudhry, A. (2013). Correlation of general anxiety and dental anxiety in children aged 3 to 5 years: A clinical survey. *Journal of international oral health: JIOH*, *5*(6), 18.

O'Donnell, S., Deitz, J., Kartin, D., Nalty, T. & Dawson, G. (2012). Sensory processing, problem behavior, adaptive behavior, and cognition in preschool children with autism spectrum disorders. *American Journal of Occupational Therapy, 66*(5), 586-94. doi: 10.5014/ajot.2012.004168.

Olak, J., Saag, M., Honkala, S., Nõmmela, R., Runnel, R., Honkala, E. & Karjalainen, S. (2013). Children's dental fear in relation to dental health and parental dental fear. *Stomatologija, Baltic Dental and Maxillofacial Journal, 15*, 26-31.

Oliveira, M. M., Colares, V. (2009). The relationship between dental anxiety and dental pain in children aged 18 to 59 months: a study in Recife, Pernambuco State, Brazil. *Cadernos de Saude Publica, 25*(4), 743-50. doi:10.1590/S0102-311X2009000400005.

O'Nions, E., Sebastian, C. L., McCrory, E., Chantiluke, K., Happé, F., & Viding, E. (2014). Neural bases of Theory of Mind in children with autism spectrum disorders and children with conduct problems and callous-unemotional traits. *Developmental Science, 17*(5), 786-796.

Oosterink, F. M., De Jongh, A., Hoogstraten, J., & Aartman, I. H. (2008). The Level of Exposure-Dental Experiences Questionnaire (LOE-DEQ): a measure of severity of exposure to distressing dental events. *European Journal of Oral Sciences, 116*(4), 353-361. doi: 10.1111/j.1600-0722.2008.00542.x.

Orellana, L. M., Martınez-Sanchis, S. & Silvestre, F. J. (2014). Training Adults and Children with an Autism Spectrum Disorder to be Compliant with a Clinical Dental Assessment Using a TEACCH-Based Approach. *Journal of Autism and Developmental Disorders, 44*, 776–785. doi 10.1007/s10803-013-1930-8.

Ozonoff, S. & Strayer, D. L. (2001). Further evidence of intact working memory in autism. *Journal of Autism and Developmental Disorders*, *31*(3), 257 – 263. doi:10.1023/A:1010794902139.

Ozsivadjian, A., Hibberd, C. & Hollocks, M. J. (2014). Brief Report: The Use of Self-Report Measures in Young People with Autism Spectrum Disorder to Access Symptoms of Anxiety, Depression and Negative Thoughts. *Journal of Autism and Developmental Disorders, 44*(4), 969-74. doi: 10.1007/s10803-013-1937-1.

Padgett, D. K. (2016). *Qualitative methods in social work research*. New York: Sage Publications.

Pandya, P., Bhambal, A., Bhambani, G., Bansal, V., Kothari, S., & Divya, K. (2016). Dental Care: Social Myths and Taboos. *People Journal of Scientific Research, 9*(2), 42-46.

Parsons, Sarah. (2014). 'Why are we an ignored group?' Mainstream educational experiences and current life satisfaction of adults on the autism spectrum from an online survey. International Journal of Inclusive Education, 19(4), 1-25. doi: 10.1080/13603116.2014.935814

Paryab, M., & Hosseinbor, M. (2013). Dental anxiety and behavioral problems: A study of prevalence and related factors among a group of Iranian children aged 6-12. *Journal of Indian Society of Pedodontics and Preventive Dentistry, 31*(2), 82-86. doi: 10.4103/0970-4388.115699.

Pinborough-Zimmerman, Satterfield, J. Miller, R., Bilder, J. Hossain, D. & McMahon, W. (2007). Communication Disorders: Prevalence and Comorbid Intellectual Disability, Autism, and Emotional/Behavioral Disorders. *American Journal of Speech-Language Pathology, 16*, 359-367. doi: 10.1044/1058-0360(2007/039).

Planche, P., & Lemonnier, E. (2012). Children with high-functioning autism and Asperger's syndrome: Can we differentiate their cognitive profile?. *Research in Autism Spectrum Disorders, 6,* 939–948. http://dx.doi.org/10.1016/j.rasd.2011.12.009.

Popping, R. (2010). Some Views on Agreement To Be Used in Content Analysis. *Quality and Quantity, 44*, 1067-78.

Potter, J. & Hepburn, A. (2005). Qualitative Interviews in Psychology: Problems and Possibilities. *Qualitative Research in Psychology, 2,* 281–307. doi: 10.1191/1478088705qp045oa.

Premack, D. & Woodruff, G. (1978). Does the chimpanzee have a theory of mind?. *Behavioral and Brain Science, 1*, 515–26. doi:10.1017/S0140525X00076512.

Pugliese, C. E., Anthony, L. G., Strang, J. F., Dudley, K., Wallace, G. L., Naiman, D. Q., Kenworthy L. (2016). Longitudinal Examination of Adaptive Behavior in Autism Spectrum Disorders: Influence of Executive Function. *J Autism Dev Disord, 46*(2), 467-77. doi: 10.1007/s10803-015-2584-5.

Rachman S. (1977). The conditioning theory of fear-acquisition: a critical examination. *Behaviour* Research and *Therapy* 15, 375-387. doi:10.1016/0005-7967(77)90041-9.

Rajendran, G. & Mitchell, P. (2007). Cognitive theories of autism. *Developmental Review, 27*, 224–260. doi:10.1016/j.dr.2007.02.001.

Ramos-Jorge, J., Marques, L. S., Homem, M. A., Paiva, S. M., Ferreira, M. C., Ferreira F. O., & Ramos-Jorge, M. L. (2013). Degree of dental anxiety in children with and without toothache: prospective assessment. *International Journal of Paediatric Dentistry*, *23*(2), 125-130.

Randall, C. L., Shaffer, J. R., McNeil, D. W., Crout, R. J., Weyant, R. J. & Marazita, M. L. (2016). Toward a genetic understanding of dental fear: evidence of heritability. *Community Dentistry and Oral Epidemiolog*y. doi: 10.1111/cdoe.12261.

Rao, S. M. & Gagie, B. (2006). Learning through seeing and doing: Visual supports for children with autism. *Teaching Exceptional Children*, *38*(6), 26-33.

Reed, P., Watts, H., & Truzoli, R. (2013). Flexibility in young people with autism spectrum disorders on a card sort task. *Autism, 17*, 162–171. doi: 10.1177/1362361311409599.

Regier, D. A., Kuhl, E. A. and Kupfer, D. J. (2013). The DSM-5: Classification and criteria changes, *World Psychiatry, 12*(2), 92–98. doi: 10.1002/wps.20050

Rice, C. E., Rosanoff, M., Dawson, G., Durkin, M.S., Croen, L. A. Singer, A. & Yeargin-Allsopp, M. (2012). Evaluating Changes in the Prevalence of the Autism Spectrum Disorders. *Public Health Reviews*, *34*(2), 1-22.

Richman, D. M.; Dotson, W. H.; Rose, C. A.; Thompson, S.; Abby, L. (2012). Effects of Age on the Types and Severity of Excessive Fear or the Absence of Fear in Children and Young Adults with Autism. *Journal of Mental Health Research in Intellectual Disabilities*, 5(3-4), 215-235. doi: 10.1080/19315864.2011.596614.

Rohner, R. P., & Khaleque, A. (2010). Testing central postulates of parental acceptance-rejection theory (PARTheory): A meta-analysis of cross-cultural studies. *Journal of Family Theory and Review, 3*, 73-87.

Rossignol, D. A., Genuis, S. J., & Frye, R. E. (2014). Environmental toxicants and autism spectrum disorders: a systematic review. *Translational Psychiatry, 4*(2), e360.

Rubin, K. H., Coplan, R. J., & Bowker, J. C. (2009). Social Withdrawal in Childhood. *Annual Review of Psychology*, 60, 11–31. doi: 10.1146/annurev.psych.60.110707.163642.

Russell, G., Rodgers, L. R., Ukoumunne, O. C., & Ford, T. (2014). Prevalence of parent-reported ASD and ADHD in the UK: findings from the Millennium Cohort Study. *Journal of autism and developmental disorders*, *44*(1), 31-40.

Rutter, M. (2005). Incidence of Autism Spectrum Disorders: Changes Over Time and their Meaning. *Acta Paediatrica*, 94, 2-15.

Ruzzano, L., Borsboo, D. & Geurts, H. M. (2015). Repetitive Behaviors in Autism and Obsessive–Compulsive Disorder: New Perspectives from a Network Analysis. *Journal of Autism and Developmental Disorders, 45*(1), 192–202. doi: 10.1007/s10803-014-2204-9.

Salem, K., Kousha, M., Anissian, A. & Shahabi, A. (2012). Dental Fear and Concomitant Factors in 3-6 Year-old Children. *Journal of Dental Research and Dental Clinics and Dental Prospects, 6*(2), 70–4. doi:0.5681/joddd.2012.015.

Sappok, T., Brooks, W., Heinrich, M., McCarthy, J. & Underwood, L. (2016). Cross-Cultural Validity of the Social Communication Questionnaire for Adults with Intellectual Developmental Disorder. *Journal of Autism and Developmental Disorders*. doi:10.1007/s10803-016-2967-2.

Savin-Baden, M., & Major, C. H. (2013). *Qualitative research: The essential guide to theory and practice*. London: Routledge.

Saxena, P., Gupta, S. K., Newaskar, V., & Chandra, A. (2013). Advances in dental local anesthesia techniques and devices: An update. *National Journal of Maxillofacial Surgery*, *4*(1), 19–24. http://doi.org/10.4103/0975-5950.117873.

Schoen, S. A., Miller, L. J., Brett-Green, B. A. & Nielsen, D. M. (2009). Physiological and behavioral differences in sensory processing: a comparison of children with autism spectrum disorder and

sensory modulation disorder. *Frontiers in Integrative Neuroscience, 3*, 29. doi: 10.3389/neuro.07.029.2009.

Schwartz, C., Snidman, N. & Kagan, J. (1999). Adolescent Social Anxiety as an Outcome of Inhibited Temperament in Childhood. *Journal of the American Academy of Child & Adolescent Psychiatry 38*, 1008-1015. doi: 10.1097/00004583-199908000-00017.

Sedgwick, P. (2014). Cross sectional studies: advantages and disadvantages. *British Medical Journal, 2*, 348-349. doi: 10.1136/bmj.g2276.

Semrud-Clikeman, M., Fine, J. G., & Bledsoe, J. (2014). Comparison among children with Autism Spectrum Disorder, nonverbal learning disorder and typically developing children on measures of executive functioning. *Journal of Autism and Developmental Disorders, 44*, 331–342. doi:10.1007/10803-013- 1871-2.

Seymour, M., Wood C., Giallo, R. Jellett, R. (2013). Fatigue, Stress and Coping in Mothers of Children with an Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 43(7)*, 1547–1554. doi 10.1007/s10803-012-1701-y.

Shapiro, M., Sgan-Cohen, H. D., Parush, S., & Melmed, R. N. (2009). Influence of adapted environment on the anxiety of medically treated children with developmental disability. *The Journal of pediatrics*, *154*(4), 546-550. doi: 10.1016/j.jpeds.2008.10.017.

Sharma, R., Mallaiah, P., Margabandhu, S., Umashankar, G., & Verma, S. (2015). Dental Myth, Fallacies and Misconceptions and its Association with Socio-Dental Impact Locus of Control Scale. *International Journal of Preventive and Public Health Sciences, 1*(2), 14-20. doi: 10.17354/ijpphs/2015/11.

Sharma, S., Woolfson, L., & Hunter, S. (2014). Maladaptive cognitive appraisals in children with high-functioning autism: Associations with fear, anxiety and theory of mind. *Autism, 18* (3), 244-254. doi: 10.1177/1362361312472556.

Shattuck, P.T. (2006). The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education. *Pediatrics*, *117*(4), 1028-37.

Sheiham, A. (2006). Dental caries affects body weight, growth and quality of life in pre-school children. *Br Dent J, 201*(10), 625-626.

Shroff, A. (2015). Pervasive Developmental Disorders (PDDs) WebMD, LLC, Retreived from http://www.webmd.com/brain/autism/development-disorder.

Silva, E.B., Filipini R., Monteiro, C.B., Valenti, V.E., de Carvalho, S.M., Wajnsztejn, R,...&de Abreu, L.(2013).The biopsychosocial processes in autism spectrum disorder. *International Archives of Medicine, 6*(1):22. doi: 10.1186/1755-7682-6-22.

Silverman, D. (2010). *Doing Qualitative Research. A Practical Handbook.*4th Ed, London: SAGE.

Silverman, D. (2016). *Qualitative research*.London: Sage.

Simonoff, E., Pickles, A., Charman, T., Chandler S, Loucas T, Baird G.. (2008) Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(8), 921–929. doi: 10.1097/CHI.0b013e318179964f.

Singh, H., Bhaskar, D.J. & Rehman, R. (2015). Psychological Aspects of Odontophobia. *Journal of International Dental and Medical Research, 1*(6), 210-212.

Sinhaa. P., Kjelgaard, M., Gandhi, T., Tsourides, K., Cardinaux, A., Pantazis, D., ... & Held, R. (2014). Autism as a disorder of prediction. *PNAS,111*(42), 15220–15225. Doi: 10.1073/pnas.1416797111.

Sinzig, J., Walter, D., & Doepfner, M. (2009). Attention Deficit/Hyperactivity Disorder in Children and Adolescents with Autism Spectrum Disorder: Symptom or Syndrome? *Journal of Attention Disorders*, 13, 117-126. doi: 10.1177/1087054708326261.

Smith, C.A. & Lazarus, R.S. (1993). Appraisal components, core relational themes, and the emotions. *Cognition and Emotion, 7*(3/4), 233-269. doi:10.1080/02699939308409189.

Smith, J. A., & Osborn, M.. (2003). Interpretative phenomenological analysis. *In J.A. Smith (Ed.), Qualitative psychology: a practical guide to research methods* (pp. 51-80). London: Sage.

Soares, F. C., Lima, R. A., Gomes de Barros, M. V., Colares, V. (2014). Original Article Factors Associated with Dental Anxiety in Brazilian Children of 5 to 8 years. *Brazilian Research in Pediatric Dentistry and Integrated Clinic. 14*(2) 97-105 doi: http://dx.doi.org/ 10.4034/PBOCI.2014.142.04 ISSN 1519-0501.

Spielberger, C. D. (2010). *State-Trait Anxiety Inventory*. The Corsini Encyclopedia of Psychology, N_Y, USA: John Wiley & Sons, Inc.

Stace, H. (2010). Student research report: Mother blaming; or autism, gender and science. *Women's Studies Journal*, *24*(2), 66.

Stein, L. I., Polido, J. C., & Cermak, S. A. (2013). Oral care and sensory over-responsivity in children with autism spectrum disorders. *Pediatric dentistry*, *35*(3), 230-235.

Stein, L.I., Polido, J.C., Mailloux, M.A., Coleman, G.G., &Cermak, S.A. (2011). Oral care and sensory sensitivities in children with autism spectrum disorders. *Special Care Dentist*, *3*, 102-110.

Stein, L. I., Lane, C. J., Williams, M. E., Dawson, M. E., Polido, J. C. and Cermak, S. A. (2014). Physiological and Behavioral Stress and Anxiety in Children with Autism Spectrum Disorders during Routine Oral Care. *BioMed Research International*. doi:10.1155/2014/694876.

Stevens, M. R., Lyles, W. & Berke, P. R. (2014). Measuring and Reporting Intercoder Reliability in Plan Quality Evaluation Research. *Journal of Planning Education and Research, 34*(1) 77–93.

Stewart, C.R., Sanchez, S.S., Grenesko, E.L., Brown, C.M., Chen, C.P., Keehn, B.,… & Müller, R.A. (2016). Sensory Symptoms and Processing of Nonverbal Auditory and Visual Stimuli in Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 46*(5), 1590-1601. doi: 10.1007/s10803-015-2367-z.

Storjord, H. P., Teodorsen, M. M., Bergdahl, J., Wynn, R., & Johnsen, J. A. K. (2014). Dental anxiety: a comparison of students of dentistry, biology, and psychology. *Journal of multidisciplinary healthcare*, *7*, 413-418.doi: 10.2147/JMDH.S69178.

Sukhodolsky, D., Bloch, M., Panza, K., & Reichow, B. (2013). Cognitive-behavioral therapy for anxiety in children with high-functioning autism: a meta-analysis. *Pediatrics, 132*(5), e1341-e1350. doi: 10.1542/peds.2013-1193.

Sullivan, P.F., Magnusson, C., Reichenberg, A., Boman, M., Dalman, C., Davidson, M., … Lichtenstein, P. (2012). Family history of schizophrenia and bipolar disorder as risk factors for autism. *Arch Gen Psychiatry, 69*(11), 1099-1103. doi:10.1001/archgenpsychiatry.2012.730.

Sullivan, S., Rai, D., Golding, J., Zammit, S. & Steer, C. (2013). The association between autism spectrum disorder and psychotic experiences in the Avon Longitudinal Study of Parents and Children (ALSPAC) birth cohort. *J Am Acad Child Adolesc Psychiatry, 52*(8), 806-814.e2. Doi:10.1016/j.jaac.2013.05.010.

Taani, D. Q., El-Qaderi, S. S., & Abu Alhaija, E. S.(2005). Dental anxiety in children and its relationship to dental caries and gingival condition. *International Journal of Dental Hygiene, 3*(2), 83-87. doi: 10.1111/j.1601-5037.2005.00127.x.

Tager-Flusberg, H. (2001). A *reexamination of the theory of mind hypothesis of autism*. Mahwah, NJ,US: Lawrence Erlbaum Associates Publishers.

Tager-Flusberg, H. (2007). Evaluating the theory-of-mind hypothesis of autism. Current Directions in Psychological Science, 16, 311-315. doi.org/10.1111/j.1467-8721.2007.00527.x.

Tavassoli, T., Hoekstra, R. A. & Baron-Cohen, S. (2014). The Sensory Perception Quotient (SPQ): development and validation of a new sensory questionnaire for adults with and without autism. *Molecular Autism, 5*(29), 1-10. doi: 10.1186/2040-2392-5-29.

Taylor, B., Jick, H., & MacLaughlin, D. (2013). Prevalence and incidence rates of autism in the UK: time trend from 2004–2010 in children aged 8 years. *BMJ open*, *3*(10), e003219.

Taylor, L., Swerdfeger, A., Eslick, G. (2014). Vaccines are not Associated with Autism: An Evidence-Based Meta-Analysis of Case-Control and Cohort Studies. Vaccine, 32(29):3623-9. doi: 10.1016/j.vaccine.2014.04.085.

Ten Berge (2008). Dental fear in children: clinical consequences. Suggested behaviour management strategies in treating children with dental fear. *European Archives of Paediatric Dentistry, 9*, 41-46. 10.1007/BF03262655.

Themessl-Huber, M., Freeman, R., Humphris, G., MacGillivray, S. & Trezi, N. (2010). Empirical evidence of the relationship between parental and child dental fear: a structure review and meta-analysis. *International Journal of Paediatric Dentisrty, 20 (2)*, 83-101. doi: 10.1111/j.1365-263X.2009.00998.x.

Tinsley, H. E. A. & Weiss, D. J. (2000). Interrater reliability and agreement. In H. E. A. Tinsley & S. D. Brown, Eds., *Handbook of Applied Multivariate Statistics and Mathematical Modeling,* pp. 95-124. San Diego, CA: Academic Press.

Tomchek, S. D. & Dunn, W, (2007). Sensory processing in children with and without autism: a comparative study using the short sensory profile. The *American Journal of Occupational Therapy, 61*, 190–200. doi:10.5014/ajot.61.2.190.

Tordjman, S., Anderson, G. M., Botbol, M., Brailly-Tabard, S., Perez-Diaz, F., Graignic, R., ... & Bronsard, G. (2009). Pain reactivity and plasma β-endorphin in children and adolescents with autistic disorder. *PLoS One*, *4*(8), e5289. doi:10.1371/journal.pone.0005289.

Towned, E., Dimigen, G. & Fung, D. A. (2000). Clinical study of child dental anxiety. *Behaviour Research and Therapy, 38(1)* , 31-46. doi:10.1016/S0005-7967(98)00205-8.

Tsai, L. Y. (2014). Impact of DSM-5 on epidemiology of Autism Spectrum Disorder. *Research in Autism Spectrum Disorders, 8*, 1454–1470.

Udhya, J., Varadharaja, M., Parthiban, J. & Srinivasan, I. (2014). Autism Disorder (AD): An Updated Review for Paediatric Dentists. *Journal of Clinical and Diagnostic Research., 8*(2), 275-279. doi.org/10.7860/JCDR/2014/7938.4080.

Uno, Y., Uchiyama, T., Kurosawa, M., Aleksic, B., & Ozaki, N. (2015). Early exposure to the combined measles–mumps–rubella vaccine and thimerosal-containing vaccines and risk of autism spectrum disorder. *Vaccine*, *33*(21), 2511-2516.

Vanegas, S. B., & Davidson, D. (2015). Investigating distinct and related contributions of Weak Central Coherence, Executive Dysfunction, and Systemizing theories to the cognitive profiles of children with Autism Spectrum Disorders and typically developing children. *Research in Autism Spectrum Disorders*, *11*, 77-92. doi:10.1016/j.rasd.2014.12.005.

Van Eylen, L., Boets, B., Steyaert, J., Wagemans, J. & Noens, I. (2015). Executive functioning in autism spectrum disorders: influence of task and sample characteristics and relation to symptom severity. *European Child & Adolescents Psychiatry, 24*(11), 1399–1417. doi 10.1007/s00787-015-0689-1.

Van den Bergh, S. F., Scheeren, A. M., Begeer, S., Koot, H. M., Geurts, H. M. (2014). Age related differences of executive functioning problems in everyday life of children and adolescents in the autism spectrum. *Journal of Autism and Developmental Disorders, 44*(8), 1959-71. doi: 10.1007/s10803-014-2071-4.

Van der Hallen, R., Evers, K., Brewaeys, K., Van den Noortgate, W., & Wagemans, J. (2015). Global processing takes time: A meta-analysis on local–global visual processing in ASD. *Psychological bulletin*, *141*(3), 549.

Van Steensel, F. J.,Bögels, S. M., & Perrin, S. (2011). Anxiety Disorders in Children and Adolescents with Autistic Spectrum Disorders: A Meta-Analysis. *Clinical Child and Family Psychology Review, 14*(3), 302-317. doi: 10.1007/s10567-011-0097-0.

Van Wijngaarden-Cremers, P. J., van Eeten, E., Groen, W. B., Van Deurzen, P. A., Oosterling, I. J., Van der Gaag, R. J. (2014). Gender and Age Differences in the Core Triad of Impairments in Autism Spectrum Disorders: A Systematic Review and Meta-analysis. *Journal of Autism Developmental Disorders, 44*, 627–635. doi 10.1007/s10803-013-1913-9.

Volkmar, F. R. and McPartland, J. C. (2014). From Kanner to DSM-5: Autism as an Evolving Diagnostic Concept. *Annual Review of Clinical Psychology*, 10, 193-212. doi: 10.1146/annurev-clinpsy-032813-153710.

Vasa, R. A., Kalb, L., Mazurek, M. Kanne, S., Freedman, B., Keefer, A., Clemons, T., Murray, D. (2013). Age-related differences in the prevalence and correlates of anxiety in youth with autism spectrum disorders. Research in Autism Spectrum Disorders, 7(11), 1358-1369. doi: 10.1016/j.rasd.2013.07.005.

Wakefield, A. J. (1999). MMR vaccination and autism. The Lancet, 354(9182), 949-950.

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

Wardle J. (1984). Dental Pessimism*:* Negative Cognitions in Fearful Dental Patients. *Behaviour Research and Therapy Journal,* 22, 553–6.

White S., Oswald D., Ollendick T, Scahil L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review, 29*, 216-229.

Wide Boman, U., Carlsson, V., Westin, M., & Hakeberg, M. (2013). Psychological treatment of dental anxiety among adults: a systematic review. *European Journal of Oral Sciences, 121*(3pt2), 225-234. doi: 10.1111/eos.12032.

Wigham, S. & McConachie, H. (2014). Systematic review of the properties of tools used to measure outcomes in anxiety intervention studies for children with Autism Spectrum Disorders. *PLoS ONE, 9*(1), 1–17. doi: 10.1371/journal.pone.0085268.

Wigham, S., Rodgers, J., South, M., McConachie, H. & Freeston, M. (2015). The Interplay Between Sensory Processing Abnormalities, Intolerance of Uncertainty, Anxiety and Restricted and Repetitive Behaviours in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 45*, 943–952. Doi 10.1007/s10803-014-2248-x.

Williams, M. T., Chapman, L. K., Wong, J. & Turkheimer, E. (2012). The Role of Ethnic Identity in Symptoms of Anxiety and Depression in African Americans. *Psychiatry Research, 199*, 31-36. doi:10.1016/j.psychres.2012.03.049.

Williams, S., Leader, G., Mannion, A., & Chen, J. (2015). An investigation of anxiety in children and adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *10*, 30-40. doi:10.1016/j.rasd.2014.10.017.

Wilson, S. (2013). Management of Child Patient Behavior: Quality of Care, Fear and Anxiety, and the Child Patient. *Pediatric Dentistry, 35*(2) S73-S77. doi: 10.1016/j.joen.2012.11.040.

Won, H., Mah, W., & Kim, E. (2013). Autism spectrum disorder causes, mechanisms, and treatments: focus on neuronal synapses. *Frontiers in molecular neuroscience*, *6*, 19.

Wood, J. J. & Gadow, K. D. (2010). Exploring the Nature and Function of Anxiety in Youth with Autism Spectrum Disorders. *Clinical Psychology: Science and Practice, 17*(4), 281–292. doi: 10.1111/j.1468-2850.2010.01220.x.

Wood, J. J., McLeod, B. D., Sigman, M., Hwang, W. C., Chu, B. C. (2003). Parenting and childhood anxiety: theory, empirical findings, and future directions. *The Journal of Child Psychology and Psychiatry, 44*(1), 134-151.doi: 10.1111/1469-7610.00106.

Woodward L. J., Fergusson, D.M. (2001) Life Course Outcomes of Young People with Anxiety Disorders in Adolescence. *Journal* of the *American Academy* of *Child* & *Adolescent Psychiatry*, 40, 1086–93.

Woolfenden, S., Sarkozy, V., Ridley, G., Coory, M., & Williams, K.(2012) A Systematic Review of Two Outcomes in Autism Spectrum Disorder: Epilepsy and Mortality. *Developmental Medicine & Child Neurology, 54*(4), 306-312. doi: 10.1111/j.1469-8749.2012.04223.x.

World Health Organisation (2009*). International Classification of Diseases, Version 10 (ICD-10).* Geneva: World Health Organisation.

Zaidman-Zait, A., Mirenda, P., Duku, E., Szatmari, P., Georgiades, S., Volden, J., ... & Fombonne, E. (2014). Examination of bidirectional relationships between parent stress and two types of problem behavior in children with autism spectrum disorder. *Journal of autism and developmental disorders*, *44*, 1908-1917. doi:10.1007/s10803-014-2064-3

Zainal. H., Magiati, I., Tan, J. W., Sung, M., Fung, D. S. & Howlin, P. (2014). A preliminary investigation of the Spence Children's Anxiety Parent Scale as a screening tool for anxiety in young people with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(8), 1982-1994. doi: 10.1007/s10803-014-2075-0.

Zhao, N., Deng, F., & Yu, C. (2014). Anesthesia for pediatric day-case dental surgery: a study comparing the classic laryngeal mask airway with nasal trachea intubation. *Journal of Craniofacial Surgery, 25*(3), e245-e248. doi: 10.1097/SCS.0000000000000547.

Zheng, M. (2015). Conceptualization of Cross-Sectional Mixed Methods Studies in Health Science: A Methodological Review. *International Journal of Quantitative and Qualitative Research Methods, 3*(2), 66-87.

Appendices

Appendix 1

ICD-10 CRITERIA FOR "CHILDHOOD AUTISM"

A. Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas:

1. Receptive or expressive language as used in social communication;
2. The development of selective social attachments or of reciprocal social interaction;
3. Functional or symbolic play.

B. A total of at least six symptoms from (1), (2) and (3) must be present, with at least two from (1) and at least one from each of (2) and (3)

1. Qualitative impairment in social interaction are manifest in at least two of the following areas:

a. Failure adequately to use eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;

b. Failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;

c. Lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behavior according to social context; or a weak integration of social, emotional, and communicative behaviors;

d. Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. a lack of showing, bringing, or pointing out to other people objects of interest to the individual).

2. Qualitative abnormalities in communication as manifest in at least one of the following areas:

a. Delay in or total lack of, development of spoken language that is not accompanied by an attempt to compensate through the use of gestures or mime as an alternative mode of communication (often preceded by a lack of communicative babbling);

b. Relative failure to initiate or sustain conversational interchange (at whatever level of language skill is present), in which there is reciprocal responsiveness to the communications of the other person;

c. Stereotyped and repetitive use of language or idiosyncratic use of words or phrases;

d. Lack of varied spontaneous make-believe play or (when young) social imitative play

3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities are

manifested in at least one of the following:

a. An encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature though not in their content or focus;

b. Apparently compulsive adherence to specific, nonfunctional routines or rituals;

c. Stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting or complex whole body movements;

d. Preoccupations with part-objects of non-functional elements of play materials (such as their order, the feel of their surface, or the noise or vibration they generate).

C. The clinical picture is not attributable to the other varieties of pervasive developmental disorders; specific development disorder of receptive language (F80.2) with secondary socio-emotional problems, reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F72) with some associated emotional or behavioral disorders; schizophrenia (F20.-) of unusually early onset; and Rett's Syndrome (F84.12).

Appendix 2
Parents' Interview Schedule

- ❖ History of child dental visits

Tell me about your child going to the dentist?

Talk to me about the last time you took your child to the dentist?

How did you know your child is afraid of the dentist?

Did your child tell you he was afraid or did he do anything to indicate he was afraid?

- ❖ Family History

What do you think as a family about the dentist? How important is it?

Does your child go with you to the dentist when you have an appointment?

Is there any other child in the family that fears the dentist?

- ❖ Child's Fear and anxiety

Tell me about your child's worries about the dentist?

Why is your child afraid of the dentist?

Are there any events, whether positive or negative that influenced your child's fear of the dentist?

- ❖ Parent's fear and anxiety

Do you have a fear or anxiety that affects you in general?

Do you feel anxious when you visit the dentist?

What makes you anxious about the dentist, is it

- The waiting in the clinic
- The smell of the clinic
- The sound of the tools
- Lying on the dentist chair
- The touching in the mouth
- The number of people around you
- Needles or injections

Do you think you child can pick up on your worries about going to the dentist?

- ❖ At the dentist

What happens when you take your child to the dentist?

What do you do to encourage your child to go to the dentist?

How do you reward your child for going to the dentist?

- ❖ Conclusion

Is there anything you would like to add?

Adult Interview schedule

- ❖ History of dental visits

Tell me about going to the dentist?

Talk to me about the last time you went to the dentist?

What did you feel and think when you went to the dentist?

Would other people be able to tell that you are worried or afraid? If so, how?

- ❖ Family and other History

What do your family (current, or family of origin) think about the dentist? How important is it?

Does anybody go with you to the dentist when you have an appointment?

Is there anybody else in the family that fears the dentist?

Do you have any other fears or anxiety that affects you in general?

- ❖ Fear and anxiety

Tell me about your worries about the dentist?

Why are you afraid of the dentist?

- What makes you anxious about the dentist: what do you think and feel about:
- The waiting in the clinic
- The smell of the clinic
- The sound of the tools
- Lying on the dentist chair
- The touching in the mouth
- The number of people around you
- Needles or injections

Are there any events, whether positive or negative that influenced your fear of the dentist?

- ❖ At the dentist

What happens when you take you go to the dentist?

What do you do to encourage yourself to go to the dentist?

Do you reward yourself for going to the dentist?

- ❖ Conclusion

Is there anything you would like to add?

Appendix 3
Adult/parent Information Sheet
The Investigation of Dental fear and Anxiety in individuals with Autism spectrum disorders

Supervisors:	Email:	Phone:
Dr Fiona Knott	f.j.knott@reading.ac.uk	0118 378 8529
Dr Tim Williams	timothy.williams@reading.ac.uk	0118 378 8529

Experimenter:

Lama Sahab L.A.A.Sahab@pgr.reading.ac.uk

What is the study about?

Dental anxiety in children with autism is a serious problem. Many children fear the dentist or refuse to have check-ups or treatment. However, there is currently very little knowledge about why children with ASD have these fears and we have few ideas at the moment about the kinds of things that might help. This is an exploratory designed to start to investigate the reasons behind dental fear and anxiety in children with ASD, by asking parents and people with ASD themselves about their worries. We hope that this small study will give us leads to follow in larger studies, and hopefully eventually we will be able to make some recommendations about helping children with dental anxiety.

Who can take part in the study?

We are looking for parents of children with ASD and individuals over 10 years with ASD to take part in the study.

Individuals with ASD must be over the age of 10 and must have some worries about going to the dentist.

Parents must be a parent of a child with ASD of any age, as long as the child is worried about going to the dentist. Parents are welcome to take part even if their child does not want to.

What do I have to do?
Participants will take part in an interview that involves questions about your experience of going to the dentist, or of taking your child to the dentist. Other questions will be about your family's views of going to the dentist, and any relevant events in your life. Children may choose to be interviewed alone, or with a parent there. The interviews will be audio recorded and then transcribed for later analysis.

The interview will be arranged at the University of Reading, your home or a venue of your choice, at a time to suit you. All investigators on this project have had DBS (Disclosure and Barring Checks) and have been approved by the School to work with children.

How long will it take?
The study will take up to an hour.

What will happen to my data if I take part?
Your data will be transcribed and then analysed using content analysis to draw out themes and ideas from participants.

Will my data be confidential?
What participants tell us will be kept confidential and securely stored, and you will only be identifiable by an anonymity number. The exception will be if a concern is raised about a child's safety. In this case, the concern will be discussed with Dr Knott or Dr Williams, Clinical Psychologists, who are supervising this study, so that support can be accessed.

The interviews will be used to design later studies. If the study is written up for publication, then quotes from the interviews may be used, but these will not include any identifying information.

What if I want to withdraw my consent?
Taking part in this study is completely voluntary; you may withdraw at any time without having to give any reason. There will be no consequences for you or your child in terms of the services you access if you choose not to take part. Please feel free to ask any questions that you may have about this study at any point.

What do I have to do next?

Contact me, Lama Sahab

EMAIL: L.A.A.Sahab@pgr.reading.ac.uk
MOBILE:07582125671
WRITE TO ME: At the above address

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Thank you for considering taking part in this study

Appendix 4

Parent's Consent Form

The Investigation of Dental fear and Anxiety in children with Autism spectrum disorders

	PLEASE INITIAL
I have seen and read a copy of the Information Sheet	
I have been given the opportunity to ask questions about the study and these have been answered to my satisfaction.	
I understand that all personal information will remain confidential and arrangements for the storage and disposal of any identifiable material have been made clear to me.	
I understand that I am free to withdraw from the study at any time, for any reason and without prejudice.	
I give permission for my interview to be audio recorded for later transcription	
I give permission for anonymous quotes from my own and my child's interviews to be used in publications.	
I understand that participation in this study will not affect any care or services myself or my child are currently receiving.	
I have been provided with a copy of this form and the Participant Information Sheet	

I am happy for myself, …… and my child, …… to participate in the study being conducted by Lama Sahab at The University of Reading.

Name (in capitals) ……

Signature …… Date ……

Researcher Signature …… Date ……

Researcher Name ……

Adult Consent Form
The Investigation of Dental fear and Anxiety in children with Autism spectrum disorders

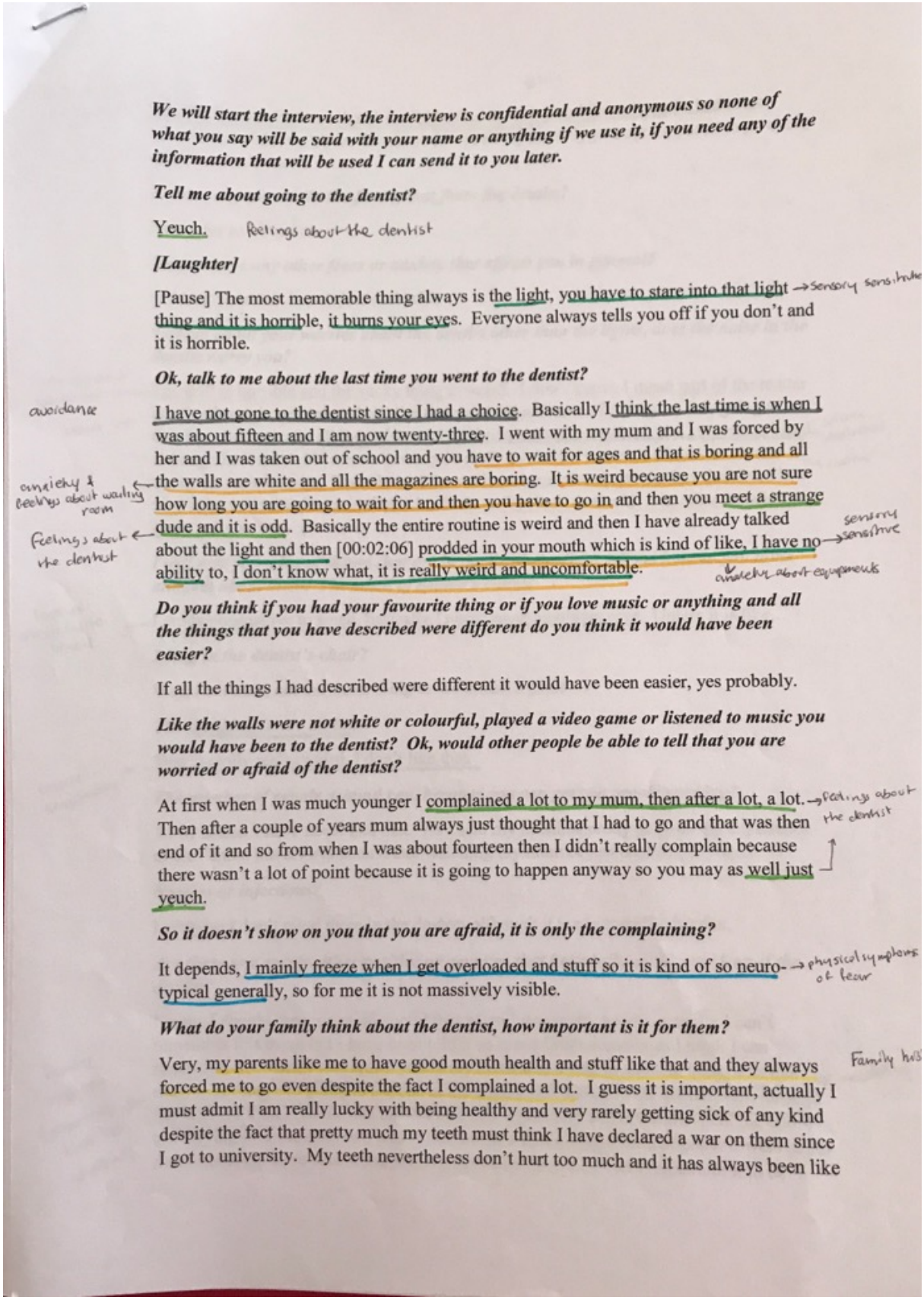
	PLEASE INITIAL
I have seen and read a copy of the Information Sheet	
I have been given the opportunity to ask questions about the study and these have been answered to my satisfaction.	
I understand that all personal information will remain confidential and arrangements for the storage and disposal of any identifiable material have been made clear to me.	
I understand that I am free to withdraw from the study at any time, for any reason and without prejudice.	
I give permission for my interview to be audio recorded for later transcription	
I give permission for anonymous quotes from my own interviews to be used in publications.	
I understand that participation in this study will not affect any care or services I am currently receiving.	
I have been provided with a copy of this form and the Participant Information Sheet	

I am happy for myself,…….……. to participate in the study being conducted by Lama Sahab at The University of Reading.

Name (in capitals)	…… ……	
Signature	…… ……	Date ……
Researcher Signature	…… ……	Date ……
Researcher Name	…… ……	

Appendix 5

Coded Adult with ASD transcript



We will start the interview, the interview is confidential and anonymous so none of what you say will be said with your name or anything if we use it, if you need any of the information that will be used I can send it to you later.

Tell me about going to the dentist?

Yeuch. Feelings about the dentist

[Laughter]

[Pause] The most memorable thing always is the light, you have to stare into that light → sensory sensitive thing and it is horrible, it burns your eyes. Everyone always tells you off if you don't and it is horrible.

Ok, talk to me about the last time you went to the dentist?

avoidance

I have not gone to the dentist since I had a choice. Basically I think the last time is when I was about fifteen and I am now twenty-three. I went with my mum and I was forced by her and I was taken out of school and you have to wait for ages and that is boring and all anxiety & feelings about waiting room ← the walls are white and all the magazines are boring. It is weird because you are not sure how long you are going to wait for and then you have to go in and then you meet a strange Feelings about the dentist ← dude and it is odd. Basically the entire routine is weird and then I have already talked about the light and then [00:02:06] prodded in your mouth which is kind of like, I have no → sensory sensitive ability to, I don't know what, it is really weird and uncomfortable. ↓ anxiety about experiences

Do you think if you had your favourite thing or if you love music or anything and all the things that you have described were different do you think it would have been easier?

If all the things I had described were different it would have been easier, yes probably.

Like the walls were not white or colourful, played a video game or listened to music you would have been to the dentist? Ok, would other people be able to tell that you are worried or afraid of the dentist?

At first when I was much younger I complained a lot to my mum, then after a lot, a lot. → Feelings about the dentist Then after a couple of years mum always just thought that I had to go and that was then end of it and so from when I was about fourteen then I didn't really complain because there wasn't a lot of point because it is going to happen anyway so you may as well just yeuch.

So it doesn't show on you that you are afraid, it is only the complaining?

It depends, I mainly freeze when I get overloaded and stuff so it is kind of so neuro- → physical symptoms of fear typical generally, so for me it is not massively visible.

What do your family think about the dentist, how important is it for them?

Very, my parents like me to have good mouth health and stuff like that and they always Family has forced me to go even despite the fact I complained a lot. I guess it is important, actually I must admit I am really lucky with being healthy and very rarely getting sick of any kind despite the fact that pretty much my teeth must think I have declared a war on them since I got to university. My teeth nevertheless don't hurt too much and it has always been like

pain

Feelings about the dentist

I dislike the dentist more than I dislike my teeth aching so I haven't really had to go. Nevertheless I haven't been for about five years, apparently you are supposed to go every couple, I don't know.

Is there anyone else in the family that fears the dentist?

Not as far as I know.

Do you have any other fears or anxiety that affects you in general?

[Pause] None that I can't just deal with.

Tell me about your worries about the dentist other than the lights, does the noise in the dentist worry you?

anxiety about equipment ← routine ←

The drill is horrible and the sucky thing is weird. I don't know, I mean part of the matter is it is a break in routine and so after that pretty much none of the rest of it is going to be that fun. So basically all the noises and all the lights and everything just gets exacerbated although how much difference that would make in itself if it wasn't a break in routine I am never entirely sure. The white of the walls and everything and the fact that there is very little natural light again that is kind of horrible but I deal with it in other situations I guess. → anxiety about the rooms

sensory sensitivities → routine

I will give you a list of things that are in the dentist's clinic, tell me how do you think and feel about them. The smell of dentist's clinic?

lack of sensitivity to smell ←

I am hyposensitive to smell, basically I never smell anything, ever. Unless it is like…

Lying in the dentist's chair?

Weird but meh, not the worst thing in the dentist I guess.

The touching in the mouth.

sensory sensitivities ←

That is really really weird, I don't like that.

The number of people around you, because you can get two people working?

To be honest I have never had that. As I said my health is pretty good so my experience in the dentist has always been either watching my mum or just prodding my teeth.

Needles or injections?

I suppose I don't mind them in the doctors although it is never really that fun.

Are there any events either positive or negative that have influenced your fear of the dentist?

Family history (experience that has no affect) ←

I guess I should mention at this point that when I was really young, actually I can't remember this event but I have been told it so many times sometimes I think I can remember it. When I was really young my mum was trying to show to both of us that there is nothing bad going to happen at the dentist and basically the dentist went through her artery, I think. There was masses of blood apparently and my mum spent the entire time trying to smile at us two whilst the dentist was shoving tonnes of paper towels in her mouth because there was blood pouring out of her mouth. I can't remember it to be

→ modelling

honest, my memory for anything past about eight or nine years ago is near enough non-existent and it happened far before that.

Do you think that has anything to do with your fear of the dentist, subconsciously?

I wouldn't know subconsciously but I don't think so to be honest. I just think I hate the break in routine and the entire thing. The break in routine, the weird stimuli, yeah.

routine ←

What happens when you go to the dentist?

What do you mean?

Tell me when you go to the dentist what do you usually do? How do you feel, how do you react when you first go in? It has been a very long time and I don't think you remember.

Well I mean…

When your mum used to take you what did you used to do?

Go in, sit in the waiting room area for a while and get bored, time kind of loses all meaning after a while. Then the doctor or dentist dude will come up and then he will say, then I will be led in. Sorry should I be describing my feelings?

Yes you can do that, you can describe what does he do to you as well, does he check your mouth?

sensory sensitivities → anxiety about equipments

Generally he just gets these wire things and prods inside my mouth and that is really weird. I don't know how to think or talk about that it is just like I don't have that happen in any other situation categorically ever. I have never, it is just, I don't know, it is just so weird, I don't know. I generally have no reason to categorise that as a thing and then it happens and I am just like I am going to pretend that didn't happen, that is just so, it is off the chart weird. I don't know in terms of my feelings, in those situations I guess it is always more a case of…

You mentioned the dentist being a stranger, do you think if your dentist was the same dentist always would you go to the dentist if you have the same dentist?

[Pause] I don't know, maybe. The problem with ritualising stuff is that you can only really ritualise it if it happens more commonly than once every couple of months. You can't really go to the dentist once every couple of months I don't think.

→ routine

It is like once every six months for a check-up.

Really?

Yes, but if you have the same dentist every six months would you go to the dentist?

I am not sure if that in itself would make a difference, if that would make me go to the dentist by itself but it would probably help.

If you had to go to the dentist what would you do to encourage yourself to go to the dentist?

[Laughter] Eat chocolate, generally in situations that is why I said since I have come to

↓ reinforcement & rewards

university my teeth think I have declared war on them because basically to get around the vast amounts of stress it is just chocolate and donuts and stuff, god knows how I haven't become fat.

That is good.

I am not looking a gift horse in the mouth.

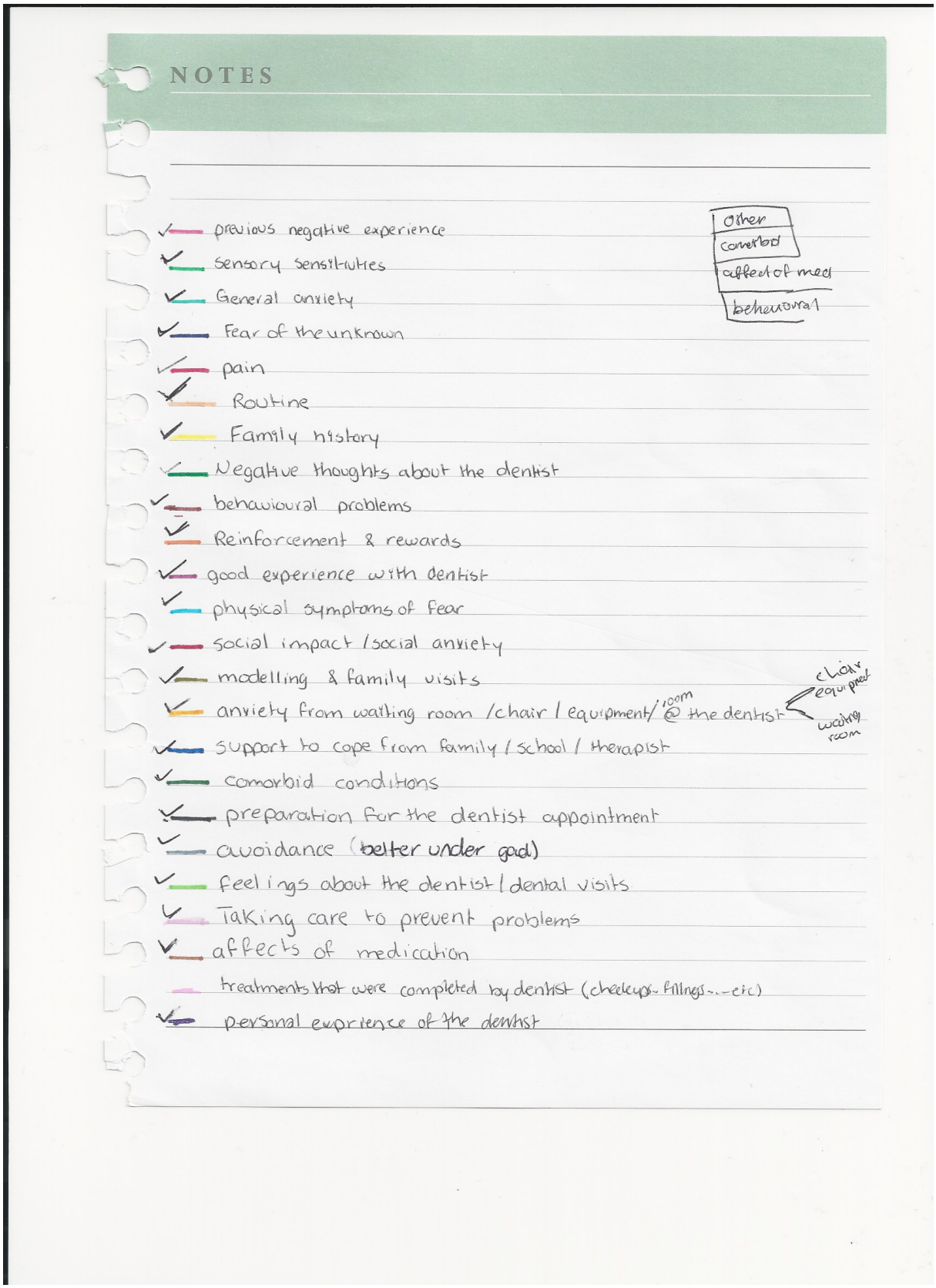
Is there anything that you would like to add?

Meh, not really.

Thank you very much for your participation.

Appendix 6

Codes used for First Qualitative Study analysis



Appendix 7

Transcript 7 coded by LS & FK 25/6/2016

Transcript	Code	Comment
I dislike it immensely. I just don't like the entire process	25	AGREE
I try to avoid it as best I can but I get quite a lot of dental problems so I can't really avoid it that much.	24	AGREE
Last time I went to the dentist I had some fillings. It was generally unpleasant	25	AGREE
I quite often don't react to the anaesthesia very well, it just doesn't affect me, and so it can be quite painful	29	AGREE
There's a whole process of them injecting me and me saying it still hurts and then them having to do it again.	29	Disagree Dr. Fiona had also 25
I'm worried that it's going to hurt, that I'm going to get pieces of tooth from getting a filling down the back of my throat	27	AGREE
I generally really dislike it	25	AGREE
I get scared that the dentist is going to sort of think that I don't brush my teeth because my teeth are bad	26	AGREE
I think my dentist can probably tell and I probably talk quite a lot about how much I dislike going to the dentist.	25	AGREE
When we were children I think we went to the dentist sort of for six month check-ups as I can remember	30	Disagree Dr.Fiona had no code
I don't think that my mum particularly likes the dentist. I think that's a throwback from when she was little and the pain medication they gave you was really bad so it did	No code	AGREE

actually really really hurt to get your teeth done.		
I guess a moderate amount of social anxiety. I don't know. Not that I can think of I guess off the top of my head. I guess mild food anxiety sometimes.	9	AGREE
It's just foods that are new. Foods that I don't know necessarily what's in them.	30	Disagree
I think it's mostly probably like waiting for it to hurt. I spend the whole time waiting for it to hurt	29	AGREE
Yeah, probably. I had one of my very very back teeth pulled when I was about seventeen because I have too many teeth or something, I don't know [laughter]. I went to get it done and they injected me and they started pulling it and I told them that it hurt and they were like, oh no, it doesn't and carried on trying to pull it and I was like it really really hurts and then eventually she was like, oh well you're imagining it so we're going to have to sedate you, which is like you have to go into this whole other thing because they've never got any appointments for it but they give you like this sedative that's meant to sort of, I don't know, you're not meant to like be able to lift a kettle for like ten hours afterwards. It did absolutely nothing.	28	AGREE

They told me I needed to get a taxi home and I just walked because it was fine. It didn't do anything anyway. Yeah, so that was pretty damaging considering I really wasn't too keen on the dentist I guess.		
I've got Dyspraxia	31	AGREE
I tend to avoid going in the first place, especially if I think that there's a problem. If I'm having pain in a tooth I'll tend to avoid going to the dentist in the first place.	24	AGREE
I guess I just think about how gross it would be to have really really manky teeth so I do it that way.	26	AGREE

Percentage of reliability = 15⁄18=0.83=83%

Appendix 8

Dentist's interview Schedule

- **About the dentist**

What is dental anxiety from your experience?

What is the importance of oral health? And how does oral health affect an individual's general well- being?

- **Fears in all children**

Many children and even adults fear the dentist. How often do you have patients who are afraid of receiving dental care?

In your experience what are the causes of dental anxiety in children?

From your knowledge, do you think that parental anxiety affects the child?

Have you ever had a situation where you have seen parental behaviour affect the child, either increasing or decreasing their fear?

When you trained, was any part of the curriculum given to working with anxious children?

From your experience, what is the best way to address fear in a dentally anxious patient?

Have any of your work or personal experiences changed what you do since you trained?

- **Fears in children with ASD**

Do you have/treat patients with special needs?

Do you treat children with autism or Asperger syndrome?

Please describe what it is like to work with children with autism. Is it different from typically developing children and if so, how?

Do you think children with autism are more likely to be dentally anxious than TD? If so, why?

In your opinion as a dentist do you think children with autism fear the same things as typically developing children?

How do you address fears and anxiety in children with ASD? Do you have a set technique or is it individualized according to the person needs?

Do you have anything you would like to add?

Appendix 9
Participant Information Sheet
Dentists' views of dental fear and anxiety in children with Autism Spectrum Disorders

Supervisors:
Dr Fiona Knott
Dr Tim Williams

Experimenter:
Lama Sahab

What is the study about?

Dental anxiety in children with autism is a serious problem. Many children fear the dentist or refuse to have check-ups or treatment. However, there is currently very little knowledge about why children with ASD have these fears and we have few ideas at the moment about the kinds of things that might help. This interview study therefore asks about the approaches dentists and dental hygienists use with children with autism, and to find out more about their experiences, knowledge, behaviours, and perspectives about this problem. We hope that our study will contribute to recommendations and guidelines about helping children with autism who have dental anxiety.

Who can take part in the study?
We are looking for dentists or dental hygienists who work with children with ASD. You do not need to be special needs dentist to take part. Any dentist or dental hygienist who has experience of children with ASD is welcome to take part.

What do I have to do?
If you agree, you will take part in an interview about your experience with children as patients, and your view of how this may differ for children with ASD.

The interview can take place over the phone or in person if you prefer, such as at the University of Reading, your clinic or a venue of your choice. The interview will be arranged at a time to suit you.
How long will it take?
The interview will take about 20-30 minutes.

What will happen to my data if I take part?
Your data will be transcribed and then analysed using content analysis to draw out themes and ideas from participants.

Will my data be confidential?
What participants tell us will be kept confidential and securely stored, and you will only be identifiable by an anonymity number.

The interviews will be used to design later studies. If the study is written up for publication, then quotes from the interviews may be used, but these will not include any identifying information.

What if I want to withdraw my consent?
Taking part in this study is completely voluntary; you may withdraw at any time without having to give any reason. Please feel free to ask any questions that you may have about this study at any point.

What do I have to do next?
Contact me, Lama Sahab

EMAIL: L.A.A.Sahab@pgr.reading.ac.uk
WRITE TO ME: At the above address

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Thank you for considering taking part in this study

Appendix 10

Consent Form

Dentists' views of dental fear and anxiety in children with Autism Spectrum Disorders

	PLEASE INITIAL
I have seen and read a copy of the Information Sheet	
I have been given the opportunity to ask questions about the study and these have been answered to my satisfaction.	
I understand that all personal information will remain confidential and arrangements for the storage and disposal of any identifiable material have been made clear to me.	
I understand that I am free to withdraw from the study at any time, for any reason and without prejudice.	
I give permission for my interview to be audio recorded for later transcription	
I give permission for anonymous quotes from my own interviews to be used in publications.	
I have been provided with a copy of this form and the Participant Information Sheet	

I am happy for myself,……. to participate in the study being conducted by Lama Sahab at The University of Reading.

Name (in capitals)

Signature Date

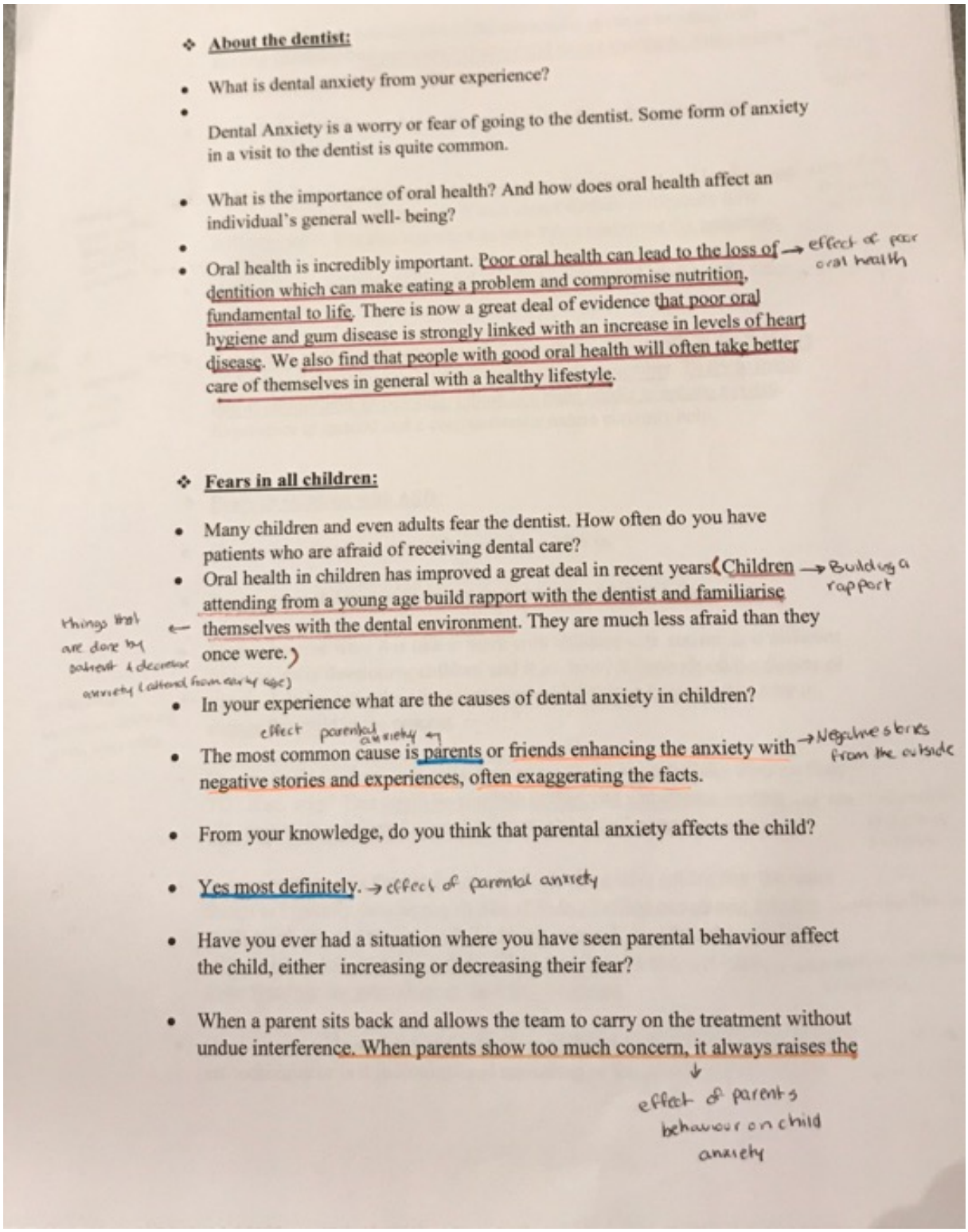
……

Contact details:

Email address

Phone

Appendix 11
Coded Dentist transcript



❖ **About the dentist:**

- What is dental anxiety from your experience?
-

Dental Anxiety is a worry or fear of going to the dentist. Some form of anxiety in a visit to the dentist is quite common.

- What is the importance of oral health? And how does oral health affect an individual's general well- being?
-
- Oral health is incredibly important. Poor oral health can lead to the loss of dentition which can make eating a problem and compromise nutrition, fundamental to life. There is now a great deal of evidence that poor oral hygiene and gum disease is strongly linked with an increase in levels of heart disease. We also find that people with good oral health will often take better care of themselves in general with a healthy lifestyle.

→ effect of poor oral health

❖ **Fears in all children:**

- Many children and even adults fear the dentist. How often do you have patients who are afraid of receiving dental care?
- Oral health in children has improved a great deal in recent years. Children attending from a young age build rapport with the dentist and familiarise themselves with the dental environment. They are much less afraid than they once were.)

→ Building a rapport

things that are done by patient to decrease anxiety (started from early age)

- In your experience what are the causes of dental anxiety in children?

effect parental anxiety

- The most common cause is parents or friends enhancing the anxiety with negative stories and experiences, often exaggerating the facts.

→ Negative stories from the outside

- From your knowledge, do you think that parental anxiety affects the child?
- Yes most definitely. → effect of parental anxiety
- Have you ever had a situation where you have seen parental behaviour affect the child, either increasing or decreasing their fear?
- When a parent sits back and allows the team to carry on the treatment without undue interference. When parents show too much concern, it always raises the

↓
effect of parents behaviour on child anxiety

anxiety of the child. I have seen this time and time again. A nervous or overly worried parent will always increase the anxiety levels in a small child.

- When you trained, was any part of the curriculum given to working with anxious children? Not particularly but we did have a paediatric clinic where we did encounter children with anxiety. → lack of preparation in dental school

- From your experience, what is the best way to address fear in a dentally anxious patient?

- Time. It is important to spend time discussing the treatment and let them ask as many questions as they need. Which aspect do they particularly have difficulty with? It is also important to take time to carry out the procedure. → providing the patient with info

strategies used with dentally anxious patient

- Have any of your work or personal experiences changed what you do since you trained?

effects of work experience on work practice

- Yes. I have really practiced giving the anaesthetic. The needle is the first part of the dental procedure and it what most patients remember. To try to make this as comfortable as possible, I think is a huge hurdle to reduce anxiety. Experience in general and a compassionate nature certainly help.

❖ **Fears in children with ASD:**

- Do you have/treat patients with special needs? Yes

- Do you treat children with autism or Asperger syndrome? Yes

- Please describe what it is like to work with children with autism. Is it different from typically developing children and if so, how? It depends on the degree of autism. I do have to take a lot more time explaining and interacting. I try to engage the child in the process.

Difference between working with ASD & TD

- Do you think children with autism are more likely to be dentally anxious than TD? If so, why? This could be possible as they can sometimes process information in a different way. Information and understanding is the key. → Information processing problems

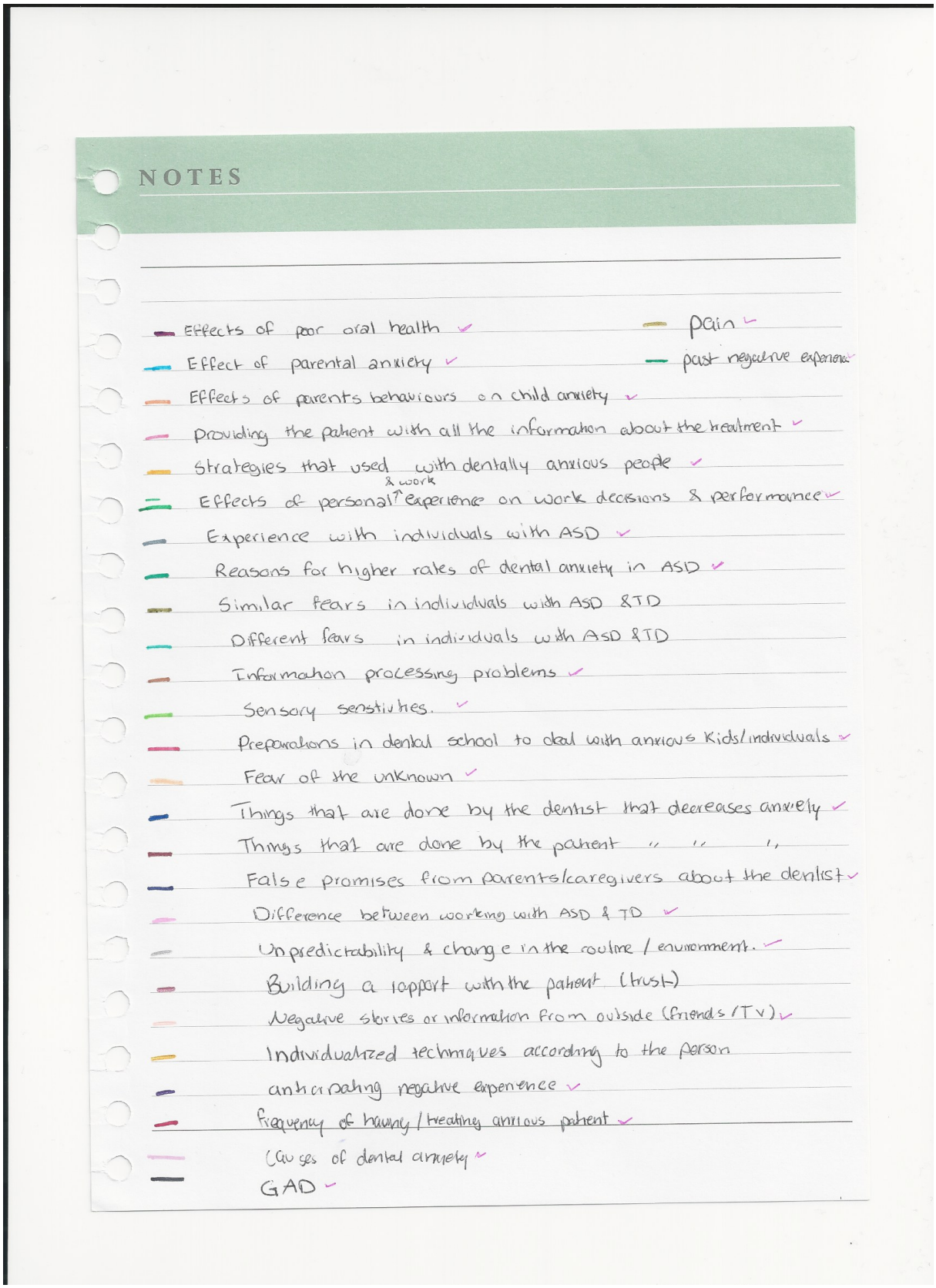
- In your opinion as a dentist do you think children with autism fear the same things as typically developing children? In my limited experience I do not really think there is too much difference as we still face the same challenges with children and dental treatment. They may have some problems understanding the procedure or their surroundings. → similar fears as TD → information processing problems

- How do you address fears and anxiety in children with ASD? Do you have a set technique or is it individualized according to the person needs? I try to

work with the patient as opposed to following a set of rules. You do have to change your approach dependant on the child and their learning or understanding capacity.

- Do you have anything you would like to add?

Appendix 12
Codes used in Second Qualitative Analysis



Appendix 13

Participant 4 FK/LS Completed 01/08/2016

Text	Code	Comment
From your experience as a dentist, what is dental anxiety? Well, dental anxiety is, well, of course if you are afraid of the dentist. And this results in less cooperation or yeah, having a hard time while at the dentist	description	Description A
What do you think of the importance of oral health? It's really important. It's important for the social interaction with other people that, yeah, the sentiment and of course also important for your health.	description	Important – social, health A
Do you think that oral health affects the individual's general wellbeing? Yes. ***So how can it affect the general wellbeing?*** Well, like I said, for the social part I think it's really important. There's just been an article published where it's describing people who have ugly looking teeth are, yeah, considered as being less like pleasant or nice. So of course that's important, but also for general health.	description	Social and health A
Many children and even adults fear the dentist. How often do you have patients who are afraid of receiving dental care? A lot because I work in a special care centre. So I see people with disabilities and people who are referred to me because of there dental anxiety. So almost everybody that I see has a history of dental anxiety	description	Experienced – special care centre A
From your experience working with dentally anxious patients, what do you think are the causes of dental anxiety in children? The cause of dental anxiety in children, having a bad experience, that happens a lot. So yeah, dentists' starts drilling without local anaesthesia,	3	3 past negative exp 2 pain 7 parental anxiety (modelling) or 11?? A

the child feels pain and gets anxious, as an example. But also children whose parents are really afraid. And yeah, so it's very afraid, and they, yeah, they see this from their parents and they also get anxious.	2 7	
Have you ever had a situation where you have seen the parents' behaviour affect their child either by increasing or decreasing their fear? Yes.	---	A
So have you ever had a situation where you had the parent and the child in the clinic and then you saw the parents' behaviour affect their child? Okay. How can you see it in the clinic? Well, I always do the extended [0:05:02], so I ask about it a lot in these anxiety questionnaires. And also parents have to fill in how afraid they are for the dentist. But I always ask parents, "How do you think, it's alright, do you think your child is now here, is going to be treated over here." And yeah, then they tell, parents often know that they are, yeah, also causing this anxiety.		11 ?parental anxiety DA
So the parents tell you that they are afraid of the dentist? Yeah, most of, yeah.	--	11 parent anxiety DA
When you were trained to be a dentist, was any part of the curriculum given to you working with anxious children? So did they teach you how to work with children with anxiety? Yeah. In dentist school, they had a paediatric dentist room, the curriculum and yeah, we have to learn about it in the [0:06:24], yeah	description	Background – training A
From your experience, not from what you were taught in the curriculum, from your experience as a dentist now, what do you think is the best way to address fear in dentally anxious patient? What's the best way to cope with dentist fear? Well, of course it depends on the child.		16 individualised techniques 13 – strategy (exposure?) A

But yeah, the different behaviour management techniques are yeah, are really important to use I think, like tell -show methods and coping exposure inhabitation. But of course it depends on the child and what is necessary.	13-16	
So your ways are individualised on the child? Yeah.	16	DA
Have any of your work or personal experience changed what you do since you trained? So for example you were trained to do something in school but from your experience you started doing something else because you believe from your experience it's better to do it the other way? Yeah. Well, at dental school we learn the basics. And yeah, then you extend your techniques during working life. So I didn't change anything but I, yeah, extended my skills I think.	intro	A
So you said you work in a special centre with people with special needs. Do you treat children with autism or Aspergers syndrome? With autism, yeah, definitely, yeah.		DA
Working with children with autism, do you think it's similar or different from typical developing children or other disabilities? No, I think it's different.	17	17 A
How is it different? Yeah. Well, people with autism, yeah, they just, yeah, they are just different than other approaches than other children, yeah.	17	17 A
Do you think they are more likely to be dentally anxious than other kids? Well, I think this is shown in research that they are. ***From what you've seen do you think they are more dentally anxious?*** Yes.		A
Can you think why they can be dentally anxious more? Because they just, yeah, I can say it. Yeah, mostly because their syndromic system just,		20 and 9 Sensory A

yeah, works different than, yeah, things are just difficult for them in the dental setting. Like there are lots of stimuli during a dental treatment and lots of things happen, there's light, there's noise, there's a feeling, so that's what makes it really difficult for them, yeah.	20-9	
How do you address, can you give me an example of how you address fear in children with autism, some of the techniques you use with children with autism that are different from other… I use pictures a lot with the children with autism. So I make pictures of all steps of treatment and so they're, yeah, they're visualising, it's something I do with autism children. And yeah, that's what I do mostly. And yeah, some children bring their headphone or something, but that's, yeah, all individualized.	12-21	12 information 21 sensory technique A

Total = 14/18=77.78%

Appendix 14

Information Sheet for Parents of participants with ASD
The Investigation of Dental fear and Anxiety in individuals with Autism spectrum disorders and typical development

Supervisors:
Dr Fiona Knott
Dr Tim Williams
Experimenter:
Lama Sahab

What is the study about?

Dental anxiety in children with autism spectrum disorders (ASD) is a serious problem. Many children fear the dentist or refuse to have check-ups or treatment. However, at the moment, we do not know very much about why children with ASD have these fears and whether they are similar to fears held by typically developing children. This study will help us start to look at the reasons behind dental fear and anxiety in children with ASD and typically developing children. We will do this by asking parents and children about their dental fears using questionnaires. We hope that this study will help us understand some of the reasons children with ASD are anxious toward the dentist and help us develop future treatments to assist them with their dental anxiety. It will also add to what we know about dental worries in children who do not have ASD.

Who can take part in the study?

We are looking for children with ASD aged between 11-16 years old and their parents, and typically developing children aged 11-16 and their parents to take part in the study. Children do not have to be worried about going to the dentist. We need people to take part if they are worried or if they are not. All children need to have a reading age of about 9 years to be able to complete the questionnaires. You are welcome to help them complete the questionnaires by explaining words that they may not understand.

We have enclosed an information sheet for young people, but you are also welcome to show older teenagers this information sheet, to explain more about the study.

If you have two or more children with ASD of the right age, then both are welcome to take part. Please ask us for more questionnaires if this is the case. If you have one child with ASD and one who is typically developing, then both are welcome to take part if they are in the right age bracket.

What should I do next?

We will post you a set of questionnaires and a stamped addressed envelope for you to return them when complete. Children will complete questionnaires about what they worry about in the dentist (if they do) and other areas such as sensory processing. Parents are welcome to help if needed. One parent will complete a series of questionnaires, about their own experience of going to the dentist, and of taking your child to the dentist. There is one additional questionnaire about your child's ASD symptoms. We think it will take about an hour to do all the questionnaires.

As a thank-you for taking part, if you agree, your child's name will be put into a draw to win an Amazon token at the end of the study. There are three tokens of £25 each as prizes.

All investigators on this project have had DBS (Disclosure and Barring Checks) and have been approved by the School to work with children.

What will happen to my data if I take part?

Your data will be analysed and written up for my PhD thesis. I would like to publish what I find in journals or at conferences. You and your child will not be identifiable in anything that is published.

Will my data be confidential?

What participants tell us will be kept confidential and securely stored. Your data stored on a password protected computer, and will only be identifiable by an anonymity number. Consent forms will be kept securely and linked to the data only by the anonymity number.

What if I want to withdraw my consent?

Taking part in this study is completely voluntary; you may withdraw at any time without having to give any reason. There will be no consequences for you or your child in terms of the services you access if you choose not to take part. Please feel free to ask any questions that you may have about this study at any point.

What do I have to do next?

Contact me, Lama Sahab

Email: L.A.A.Sahab@pgr.reading.ac.uk
Mobile: 07582 125671
Write to me: at the above address

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Thank you for considering taking part in this study

Appendix 15

Information Sheet for parent of Typical developing children
The Investigation of Dental fear and Anxiety in individuals with Autism spectrum disorders and typical development

Supervisors:
Dr Fiona Knott
Dr Tim Williams

Experimenter:
Lama Sahab

What is the study about?

Dental anxiety in children, whether or not they have autism or are typically developing, can be a serious problem. Many children fear the dentist or refuse to have check-ups or treatment. Children with autism are even more likely to be afraid than other children and at the moment we do not know why this is. This study will help us start to look at the reasons behind dental fear and anxiety in children. We will do this by asking parents and children about their dental fears using questionnaires. We hope that this study will help us understand the reasons children are anxious toward the dentist and help us develop future treatments to assist them with their dental anxiety.

Who can take part in the study?

We are looking for children aged between 11-16 years old and a parent, to take part in the study. Children do not have to be worried about going to the dentist; we need people to take part if they are worried or if they are not. Some children in the study will have ASD and others will not.

All children need to have a reading age of about 9 years to be able to complete the questionnaires. You are welcome to help them complete the questionnaires by explaining words that they may not understand.

We have enclosed a information sheet for young people, but you are also welcome to show older teenagers this information sheet, to explain more about the study.

If you have two or more children of the right age, then both are welcome to take part. Please ask us for more questionnaires if this is the case.

What should I do next?
We will post you a set of questionnaires and a stamped addressed envelope for you to return them when complete. Parents will complete a series of questionnaires, which include questions about your experience of going to the dentist, and of taking your child to the dentist. Other questionnaires will be about your child. Children will complete questionnaires about what they worry about in the dentist (if they do) and other areas such as sensory processing.

As a thank you for taking part, if you agree, your child's name will be put into a draw to win an Amazon token at the end of the study. There are three tokens of £25 each as prizes.

All investigators on this project have had DBS (Disclosure and Barring Checks) and have been approved by the School to work with children.

What will happen to my data if I take part?
Your data will be analysed and written up for my PhD thesis. I would like to publish what I find in journals or at conferences. You and your child will not be identifiable in anything that is published.

Will my data be confidential?
What participants tell us will be kept confidential and securely stored. Your data stored on a password protected computer, and will only be identifiable by an anonymity number. Consent forms will be kept securely and linked to the data only by the anonymity number.

What if I want to withdraw my consent?
Taking part in this study is completely voluntary; you may withdraw at any time without having to give any reason. There will be no consequences for you or your child in terms of the services you access if you choose not to take part. Please feel free to ask any questions that you may have about this study at any point.

What do I have to do next?

Contact me, Lama Sahab

Email: L.A.A.Sahab@pgr.reading.ac.uk
Mobile: 07582 125671
Write to me: at the above address

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Thank you for considering taking part in this study

Appendix 16

Children Information Sheet

Finding out about children's fear of going to the dentist

HI !!

My name is Lama and I would like you to help me answer some questions. I want to find out what makes children worried about going to the dentist. Please read this brochure and talk to your mum or dad to help you to choose whether you want to take part or not.

What is the research about?

I want to find out about what children think and feel when they go to the dentist. Sometimes children feel worried and sometimes they feel scared. However, other children don't mind going to the dentist at all. I want to know more about this so we can think of things that might be helpful when children go to the dentist.

What will happen to me if I choose to take part?

You will receive some questions that I want you to answer. If you get tired, complete them the next day.

Will anything in the research upset me?

I would like you to think about things that you feel at the dentist. This could upset you but if there is something you don't understand, that's OK.

Will the things I write and do be kept private?

Everything you write will be private and no one will know your name. None of your friends or teachers will see the answers or the questions or know about any of the things we do together.

What if I don't want to take part?

That's OK; you can choose whether you want to take part or not. Tell your mum or dad what you want to do and they will let me know. If you change your mind once
you have taken part, you will be allowed to stop straight away, nobody will be angry with you if you decide to stop.

Who can I talk to about whether I want to take part?

You should talk to your mum or dad before you make your mind up..

Thank you for reading this. Please ask any questions if you need to.

Appendix 17

Parent's Consent Form

The Investigation of Dental fear and Anxiety in children with Autism spectrum disorders

	PLEASE INITIAL
I have seen and read a copy of the Information Sheet	
I have been given the opportunity to ask questions about the study and these have been answered to my satisfaction.	
I understand that all personal information will remain confidential and arrangements for the storage and disposal of any identifiable material have been made clear to me.	
I understand that I am free to withdraw from the study at any time, for any reason and without prejudice.	
I have been provided with a copy of this form and the Participant Information Sheet	

I am happy for myself, …… and my child, …… to participate in the study being conducted by Lama Sahab at The University of Reading.

Name (capitals) Date

Signature

Child Consent Form
The Investigation of children's dental fear and anxiety

	PLEASE INITIAL
I understand what this study is about.	
I talked to my mum or dad about taking part in this study.	

I am happy for myself, …… to participate in the study being conducted by Lama Sahab at The University of Reading.

Name (in capitals) Date

Signature Date

Appendix 18

PARTICIPANTS NEEDED

DENTAL FEAR AND ANXIETY IN YOUNG PEOPLE

Many people feel worried about going to the dentist, but others do not have any fears at all. I am trying to find out more about this as part in my PhD research at the University of Reading. I would like young people aged between 11 and 17 and a parent to take part in the study by filling in some questionnaires which I will post to you. You do not have to be worried about the dentist to take part! If you are interested, please contact me and I will send you some information about the study.

To show our appreciation for your participation , children will be awarded a **£20 amazon voucher**.

If you are interested or for more information please contact me,
Lama Sahab on
Email: L.A.A.Sahab@pgr.reading.ac.uk

Appendix 19
ASD demographic questionnaire

When is your child's date of birth	
What is your child's gender?	Male Female
What is your child's ethnicity? Please tick	**White** 1. English / Welsh / Scottish / Northern Irish / British 2. Irish 3. Gypsy or Irish Traveller 4. Any other White background, please describe **Mixed / Multiple ethnic groups** 5. White and Black Caribbean 6. White and Black African 7. White and Asian 8. Any other Mixed / Multiple ethnic background, please describe **Asian / Asian British** 9. Indian 10. Pakistani 11. Bangladeshi 12. Chinese 13. Any other Asian background, please describe **Black / African / Caribbean / Black British** 14. African 15. Caribbean 16. Any other Black / African / Caribbean background, please describe **Other ethnic group** 17. Arab 18. Any other ethnic group, please describe
When was your child diagnosed with ASD?	
What is your child diagnosis?	
Does your child have any other diagnosis (e.g. ADHD, Anxiety, epilepsy, etc.…)	
Does your child take any medication regularly?	

What type of school does your child go to? Please tick	Mainstream, Special school ASD resource Home educated Other (please describe)

Demographic questionnaire for typically developing group

When is your child's date of birth	
What is your child's gender?	Male Female
What is your child's ethnicity? Please tick	White 1. English / Welsh / Scottish / Northern Irish / British 2. Irish 3. Gypsy or Irish Traveller 4. Any other White background, please describe **Mixed / Multiple ethnic groups** 5. White and Black Caribbean 6. White and Black African 7. White and Asian 8. Any other Mixed / Multiple ethnic background, please describe **Asian / Asian British** 9. Indian 10. Pakistani 11. Bangladeshi 12. Chinese 13. Any other Asian background, please describe **Black / African / Caribbean / Black British** 14. African 15. Caribbean 16. Any other Black / African / Caribbean background, please describe **Other ethnic group** 17. Arab 18. Any other ethnic group, please describe
Does your child have any diagnosis (e.g. ADHD, Anxiety, epilepsy, etc.…)	
Does your child take any medication regularly?	
What type of school does your child go to? Please tick	Mainstream, Special school Home educated Other (please describe)
Relationship of the person filling the questionnaires to the child	Father Mother

	Grandparent Other
Parent/guardian email for amazon voucher	

Appendix 20

Child Fear Survey Schedule –DS (CFSS-DS)

Many children are very worried about going to the dentist and some children and teenagers will not go at all. Please tell me how worried you are by circling the number that shows how you feel.

1 = Not afraid at all, 2 = Very little fear, 3= Moderate Fear, 4= Pretty afraid, 5=Very afraid

Item					
1. Dentists	1	2	3	4	5
2. Doctors	1	2	3	4	5
3. Injections	1	2	3	4	5
4. Having somebody examine the mouth	1	2	3	4	5
5. Having to open your mouth	1	2	3	4	5
6. Having a stranger touch you	1	2	3	4	5
7. Having somebody look at you	1	2	3	4	5
8. The dentist drilling	1	2	3	4	5
9. The sight of the dentist drilling	1	2	3	4	5
10. The noise of the dentist drilling	1	2	3	4	5
11. Having someone put instruments in your mouth	1	2	3	4	5
12. Choking	1	2	3	4	5
13. Having to go to the hospital	1	2	3	4	5
14. People in white uniforms	1	2	3	4	5
15. Having the nurse clean your teeth	1	2	3	4	5

Appendix 21

Dental Cognitive questionnaire

Some children are very worried about going to the dentist and can have thoughts that affect their visits to the dentist. You may not have any of these worries but can you tell me what you think about the following statements:

Worries about the Dentists		
I think Dentists do as they please	Yes	NO
I think Dentists are often impatient	Yes	NO
I think dentists do not care if it hurts	Yes	NO
I think dentists do not understand me	Yes	NO
I think dentists are often not good at their job	Yes	NO
I think dentists think I am acting childish	Yes	NO
I think treatment won't work	Yes	NO
Worries about Self		
I think my teeth are embarrassing	Yes	NO
I think I can't stand pain	Yes	NO
I think I am a nervous person	Yes	NO
Worries about treatment		
When people go to the dentist, they have check-ups. Sometimes they have their teeth cleaned. They might have an injection or a filing. You may not have had these but I am still interested in what you think.		
I think it will hurt when the dentist checks my teeth	Yes	NO
I think it will hurt when the dentist cleans my teeth	Yes	NO
I think everything will go wrong	Yes	NO
I think the treatment will hurt	Yes	NO
I think I can't tell the dentist when to stop	Yes	NO
I think I will get out of control	Yes	NO
I think I am locked in, I can't escape	Yes	NO
I think the injections won't numb my teeth	Yes	NO
I think I will be scared of the sound of the drill	Yes	NO
I think I will be scared of the moving chair	Yes	NO
I think that the dentist will drill in my tongue, gums, or cheek	Yes	NO
I think I have no control over what happens	Yes	NO
I think I will panic during treatment	Yes	NO
I think I will faint during treatment	Yes	NO
I think I will have trouble breathing during treatment	Yes	NO

I think I can’t stand this treatment for long	Yes	NO
I think it will hurt after treatment	Yes	NO
I think that the filling will fall out and must be done again	Yes	NO
I think I will become ill	Yes	NO

Appendix 22

Adult/Adolescent Sensory Profile

ADOLESCENT/ADULT

SENSORY PROFILE™

Catana Brown, Ph.D., OTR, FAOTA
Winnie Dunn, Ph.D., OTR, FAOTA

Self Questionnaire

Name: _____ Age: _____ Date: _____

Birthdate: _____ Gender: ☐ Male ☐ Female

Are there aspects of daily life that are not satisfying to you? If yes, please explain. _____

_____

_____

_____

INSTRUCTIONS

Please check the box that **best** describes the frequency with which you perform the following behaviors. If you are unable to comment because you have not experienced a particular situation, please draw an X through that item's number. Write any comments at the end of each section.

Please answer all of the statements. Use the following key to mark your responses:

ALMOST NEVER	When presented with the opportunity, you **almost never** respond in this manner (about 5% or less of the time).
SELDOM	When presented with the opportunity, you **seldom** respond in this manner (about 25% of the time).
OCCASIONALLY	When presented with the opportunity, you **occasionally** respond in this manner (about 50% of the time).
FREQUENTLY	When presented with the opportunity, you **frequently** respond in this manner (about 75% of the time).
ALMOST ALWAYS	When presented with the opportunity, you **almost always** respond in this manner (about 95% or more of the time).

PEARSON

Printed in the United States of America.
26 A B C D E

PsychCorp

0761649727

Item		A. Taste/Smell Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	1	I leave or move to another section when I smell a strong odor in a store (for example, bath products, candles, perfumes).					
	2	I add spice to my food.					
	3	I don't smell things that other people say they smell.					
	4	I enjoy being close to people who wear perfume or cologne.					
	5	I only eat familiar foods.					
	6	Many foods taste bland to me (in other words, food tastes plain or does not have a lot of flavor).					
	7	I don't like strong tasting mints or candies (for example, hot/cinnamon or sour candy).					
	8	I go over to smell fresh flowers when I see them.					

Comments

Item		B. Movement Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	9	I'm afraid of heights.					
	10	I enjoy how it feels to move about (for example, dancing, running).					
	11	I avoid elevators and/or escalators because I dislike the movement.					
	12	I trip or bump into things.					
	13	I dislike the movement of riding in a car.					
	14	I choose to engage in physical activities.					
	15	I am unsure of footing when walking on stairs (for example, I trip, lose balance, and/or need to hold the rail).					
	16	I become dizzy easily (for example, after bending over, getting up too fast).					

Comments

Item		C. Visual Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	17	I like to go to places that have bright lights and that are colorful.					
	18	I keep the shades down during the day when I am at home.					
	19	I like to wear colorful clothing.					
	20	I become frustrated when trying to find something in a crowded drawer or messy room.					
	21	I miss the street, building, or room signs when trying to go somewhere new.					
	22	I am bothered by unsteady or fast moving visual images in movies or TV.					
	23	I don't notice when people come into the room.					
	24	I choose to shop in smaller stores because I'm overwhelmed in large stores.					
	25	I become bothered when I see lots of movement around me (for example, at a busy mall, parade, carnival).					
	26	I limit distractions when I am working (for example, I close the door, or turn off the TV).					

Comments

Item		D. Touch Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	27	I dislike having my back rubbed.					
	28	I like how it feels to get my hair cut.					
	29	I avoid or wear gloves during activities that will make my hands messy.					
	30	I touch others when I'm talking (for example, I put my hand on their shoulder or shake their hands).					
	31	I am bothered by the feeling in my mouth when I wake up in the morning.					
	32	I like to go barefoot.					
	33	I'm uncomfortable wearing certain fabrics (for example, wool, silk, corduroy, tags in clothing).					
	34	I don't like particular food textures (for example, peaches with skin, applesauce, cottage cheese, chunky peanut butter).					
	35	I move away when others get too close to me.					
	36	I don't seem to notice when my face or hands are dirty.					
	37	I get scrapes or bruises but don't remember how I got them.					
	38	I avoid standing in lines or standing close to other people because I don't like to get too close to others.					
	39	I don't seem to notice when someone touches my arm or back.					

Comments

Item		E. Activity Level	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	40	I work on two or more tasks at the same time.					
	41	It takes me more time than other people to wake up in the morning.					
	42	I do things on the spur of the moment (in other words, I do things without making a plan ahead of time).					
	43	I find time to get away from my busy life and spend time by myself.					
	44	I seem slower than others when trying to follow an activity or task.					
	45	I don't get jokes as quickly as others.					
	46	I stay away from crowds.					
	47	I find activities to perform in front of others (for example, music, sports, acting, public speaking, and answering questions in class).					
	48	I find it hard to concentrate for the whole time when sitting in a long class or a meeting.					
	49	I avoid situations where unexpected things might happen (for example, going to unfamiliar places or being around people I don't know).					

Comments

Item		F. Auditory Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	50	I hum, whistle, sing, or make other noises.					
	51	I startle easily at unexpected or loud noises (for example, vacuum cleaner, dog barking, telephone ringing).					
	52	I have trouble following what people are saying when they talk fast or about unfamiliar topics.					
	53	I leave the room when others are watching TV, or I ask them to turn it down.					
	54	I am distracted if there is a lot of noise around.					
	55	I don't notice when my name is called.					
	56	I use strategies to drown out sound (for example, close the door, cover my ears, wear ear plugs).					
	57	I stay away from noisy settings.					
	58	I like to attend events with a lot of music.					
	59	I have to ask people to repeat things.					
	60	I find it difficult to work with background noise (for example, fan, radio).					

Comments

Summary Score Sheet

Quadrant Grid

Instructions: Transfer from the *Self Questionnaire* the item raw score that corresponds with each item listed (refer to the *User's Manual* for directions on how to obtain item raw scores). Add the Raw Score column to get the Quadrant Raw Score Total for each quadrant.

QUADRANT 1	
Low Registration	
Item	Raw Score
3	
6	
12	
15	
21	
23	
36	
37	
39	
41	
44	
45	
52	
55	
59	
Quadrant Raw Score Total	

QUADRANT 2	
Sensation Seeking	
Item	Raw Score
2	
4	
8	
10	
14	
17	
19	
28	
30	
32	
40	
42	
47	
50	
58	
Quadrant Raw Score Total	

QUADRANT 3	
Sensory Sensitivity	
Item	Raw Score
7	
9	
13	
16	
20	
22	
25	
27	
31	
33	
34	
48	
51	
54	
60	
Quadrant Raw Score Total	

QUADRANT 4	
Sensation Avoiding	
Item	Raw Score
1	
5	
11	
18	
24	
26	
29	
35	
38	
43	
46	
49	
53	
56	
57	
Quadrant Raw Score Total	

SCORE KEY	
1	Almost Never
2	Seldom
3	Occasionally
4	Frequently
5	Almost Always

ICON KEY	
—	Low Registration
ς	Sensation Seeking
◎	Sensory Sensitivity
|	Sensation Avoiding

Quadrant Summary

Instructions: Choose the appropriate Quadrant Summary Chart and then transfer the Quadrant Raw Score Total from the previous page to the corresponding Quadrant Raw Score Total box. Plot these totals by marking an X in the appropriate classification column (Much Less than Most People, Less than Most People, etc.)*

Quadrant Summary Chart for Ages 11–17

Quadrant	Quadrant Raw Score Total	Much Less Than Most People	Less Than Most People	Similar To Most People	More Than Most People	Much More Than Most People
		– –	–	=	+	+ +
1. Low Registration	/75	15 ---------- 18	19 ---------- 26	27 ---------- 40	41 ---------- 51	52 ---------- 75
2. Sensation Seeking	/75	15---------- 27	28 ---------- 41	42 ---------- 58	59 ---------- 65	66 ---------- 75
3. Sensory Sensitivity	/75	15 ---------- 19	20 ---------- 25	26 ---------- 40	41 ---------- 48	49 ---------- 75
4. Sensation Avoiding	/75	15 ---------- 18	19 ---------- 25	26 ---------- 40	41 ---------- 48	49 ---------- 75

*Classifications are based on the performance of individuals without disabilities ($n = 193$).

Quadrant Summary Chart for Ages 18–64

Quadrant	Quadrant Raw Score Total	Much Less Than Most People	Less Than Most People	Similar To Most People	More Than Most People	Much More Than Most People
		– –	–	=	+	+ +
1. Low Registration	/75	15 ---------- 18	19 ---------- 23	24 ---------- 35	36 ---------- 44	45 ---------- 75
2. Sensation Seeking	/75	15 ---------- 35	36 ---------- 42	43 ---------- 56	57 ---------- 62	63 ---------- 75
3. Sensory Sensitivity	/75	15 ---------- 18	19 ---------- 25	26 ---------- 41	42 ---------- 48	49 ---------- 75
4. Sensation Avoiding	/75	15 ---------- 19	20 ---------- 26	27---------- 41	42 ---------- 49	50 ---------- 75

*Classifications are based on the performance of individuals without disabilities ($n = 496$).

Quadrant Summary Chart for Ages 65 and older

Quadrant	Quadrant Raw Score Total	Much Less Than Most People	Less Than Most People	Similar To Most People	More Than Most People	Much More Than Most People
		– –	–	=	+	+ +
1. Low Registration	/75	15 ---------- 19	20 ---------- 26	27 ---------- 40	41 ---------- 51	52 ---------- 75
2. Sensation Seeking	/75	15 ---------- 28	29 ---------- 39	40 ---------- 52	53 ---------- 63	64 ---------- 75
3. Sensory Sensitivity	/75	15 ---------- 18	19 ---------- 25	26 ---------- 41	42 ---------- 48	49 ---------- 75
4. Sensation Avoiding	/75	15 ---------- 18	19 ---------- 25	26 ---------- 42	43 ---------- 49	50 ---------- 75

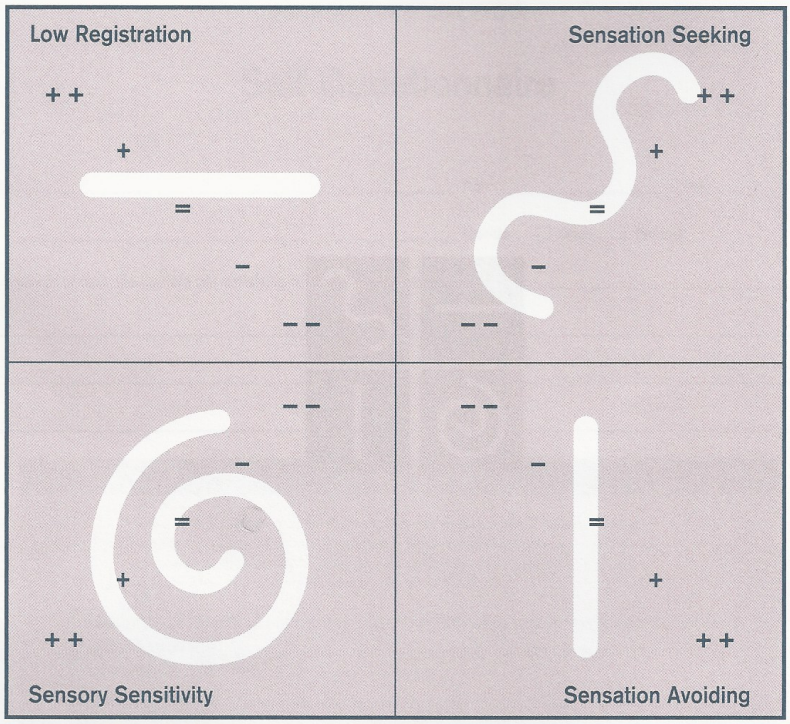
*Classifications are based on the performance of individuals without disabilities ($n = 261$).

Quadrant Profile

Instructions: Transfer the information from the classification columns of the Quadrant Summary Chart (the areas marked with an X) to the Quadrant Profile. Circle the classification symbol in each quadrant below that corresponds with the classification information for that quadrant. Finally, check the appropriate age box.

The following symbols are used to represent the classifications on the Quadrant Profile:

- – – Much Less Than Most People
- – Less Than Most People
- = Similar to Most People
- + More Than Most People
- + + Much More Than Most People



See chapter 5 for more information regarding interpretations and intervention.

Check the correct age:

- ☐ 11–17 years
- ☐ 18–64 years
- ☐ 65 years and older

Appendix 23

SPENCE CHILDREN'S ANXIETY SCALE

Your Name: _____ **Date:** _____

PLEASE PUT A CIRCLE AROUND THE WORD THAT SHOWS HOW OFTEN EACH OF THESE THINGS HAPPEN TO YOU. THERE ARE NO RIGHT OR WRONG ANSWERS.

1.	I worry about things.....	Never	Sometimes	Often	Always
2.	I am scared of the dark.....	Never	Sometimes	Often	Always
3.	When I have a problem, I get a funny feeling in my stomach.....	Never	Sometimes	Often	Always
4.	I feel afraid.....	Never	Sometimes	Often	Always
5.	I would feel afraid of being on my own at home.....	Never	Sometimes	Often	Always
6.	I feel scared when I have to take a test.....	Never	Sometimes	Often	Always
7.	I feel afraid if I have to use public toilets or bathrooms.....	Never	Sometimes	Often	Always
8.	I worry about being away from my parents.....	Never	Sometimes	Often	Always
9.	I feel afraid that I will make a fool of myself in front of people.....	Never	Sometimes	Often	Always
10.	I worry that I will do badly at my school work.....	Never	Sometimes	Often	Always
11.	I am popular amongst other kids my own age.....	Never	Sometimes	Often	Always
12.	I worry that something awful will happen to someone in my family.....	Never	Sometimes	Often	Always
13.	I suddenly feel as if I can't breathe when there is no reason for this.....	Never	Sometimes	Often	Always
14.	I have to keep checking that I have done things right (like the switch is off, or the door is locked).....	Never	Sometimes	Often	Always
15.	I feel scared if I have to sleep on my own.....	Never	Sometimes	Often	Always
16.	I have trouble going to school in the mornings because I feel nervous or afraid.....	Never	Sometimes	Often	Always
17.	I am good at sports.....	Never	Sometimes	Often	Always
18.	I am scared of dogs.....	Never	Sometimes	Often	Always
19.	I can't seem to get bad or silly thoughts out of my head.....	Never	Sometimes	Often	Always
20.	When I have a problem, my heart beats really fast.....	Never	Sometimes	Often	Always
21.	I suddenly start to tremble or shake when there is no reason for this...	Never	Sometimes	Often	Always
22.	I worry that something bad will happen to me.....	Never	Sometimes	Often	Always
23.	I am scared of going to the doctors or dentists.....	Never	Sometimes	Often	Always
24.	When I have a problem, I feel shaky.....	Never	Sometimes	Often	Always
25.	I am scared of being in high places or lifts (elevators).....	Never	Sometimes	Often	Always

26.	I am a good person.....	Never	Sometimes	Often	Always
27.	I have to think of special thoughts to stop bad things from happening (like numbers or words).....	Never	Sometimes	Often	Always
28	I feel scared if I have to travel in the car, or on a Bus or a train.....	Never	Sometimes	Often	Always
29.	I worry what other people think of me.....	Never	Sometimes	Often	Always
30.	I am afraid of being in crowded places (like shopping centres, the movies, buses, busy playgrounds).....	Never	Sometimes	Often	Always
31.	I feel happy.....	Never	Sometimes	Often	Always
32.	All of a sudden I feel really scared for no reason at all.....	Never	Sometimes	Often	Always
33.	I am scared of insects or spiders.....	Never	Sometimes	Often	Always
34.	I suddenly become dizzy or faint when there is no reason for this.....	Never	Sometimes	Often	Always
35.	I feel afraid if I have to talk in front of my class.....	Never	Sometimes	Often	Always
36.	My heart suddenly starts to beat too quickly for no reason.....	Never	Sometimes	Often	Always
37.	I worry that I will suddenly get a scared feeling when there is nothing to be afraid of.....	Never	Sometimes	Often	Always
38.	I like myself.....	Never	Sometimes	Often	Always
39.	I am afraid of being in small closed places, like tunnels or small rooms.	Never	Sometimes	Often	Always
40.	I have to do some things over and over again (like washing my hands, cleaning or putting things in a certain order).....	Never	Sometimes	Often	Always
41.	I get bothered by bad or silly thoughts or pictures in my mind.....	Never	Sometimes	Often	Always
42.	I have to do some things in just the right way to stop bad things happening.....	Never	Sometimes	Often	Always
43.	I am proud of my school work.....	Never	Sometimes	Often	Always
44.	I would feel scared if I had to stay away from home overnight.....	Never	Sometimes	Often	Always
45.	Is there something else that you are really afraid of?.....	YES	NO		
	Please write down what it is_____				
	_____				
	_____				
	How often are you afraid of this thing?.....	Never	Sometimes	Often	Always

Appendix 24
Dental Experiences Questionnaire

	OFTEN	SOMETIMES	NEVER
Please indicate about any dental treatments and check-ups that your child has had:			
My child attends for check ups			
My child has his/her teeth cleaned by the dentist or hygienist			
My child has had fluoride varnish or fissure sealants			
My child has had a filling			
My child has had an injection at the dentist			
My child has had root canal treatment			
My child has had a tooth extracted			
My child has had a dental crown			
My child has had orthodontic work (eg braces)			
Please indicate about any unpleasant experiences that your child may have had:			
My child has been criticized by a dentist			
My child has been in a situation where a dentist did not seem to understand him/her			
My child has been to a dentist who did not give him or her information about what was going to happen			
My child had an impolite or rude dentist			
Please indicate about painful experiences that your child may have had			
My child had an injection by a dentist that caused a lot of pain			
My child had a filling that hurt a lot			
My child had root canal work that hurt a lot			
My child suffered from extreme pain after a dental treatment			
My child felt sick during dental treatment			
My child almost suffocated during treatment			
Please indicate about worrying things your child might have heard about or seen			
My child has heard frightening stories about people's dental experiences			
My child has heard information in the media about dental treatments that worried them			
My child saw someone have painful dental work			
My child saw someone who was very worried at the dentist			

Appendix 25

Hospital Anxiety and Depression Scale (HADS)

You are asked to choose one response from the four given for each question. You should give an immediate response and be dissuaded from thinking too long about their answers.

	I feel tense or 'wound up':	Tick	
A	Most of the time		3
	A lot of the time		2
	From time to time, occasionally		1
	Not at all		0

	I still enjoy the things I used to enjoy:	Tick	
D	Definitely as much		0
	Not quite so much		1
	Only a little		2
	Hardly at all		3

	I get a sort of frightened feeling as if something awful is about to happen:	Tick	
A	Very definitely and quite badly		3
	Yes, but not too badly		2
	A little, but it doesn't worry me		1
	Not at all		0

	I can laugh and see the funny side of things:	Tick	
D	As much as I always could		0
	Not quite so much now		1
	Definitely not so much now		2
	Not at all		3

	Worrying thoughts go through my mind:	Tick	
A	A great deal of the time		3
	A lot of the time		2
	From time to time, but not too often		1
	Only occasionally		0

	I feel cheerful	Tick	
D	Not at all		3
	Not often		2
	Sometimes		1
	Most of the time		0

	I can sit at ease and feel relaxed:	Tick	
A	Definitely		0
	Usually		1
	Not often		2
	Not at all		3

	I feel as if I am slowed down	Tick	
D	Nearly all the time		3
	Very often		2

	Sometimes		1
	Not at all		0

A	**I get a sort of frightened feeling like 'butterflies' in the stomach**	Tick	
	Not at all		0
	Occasionally		1
	Quite Often		2
	Very Often		3

D	**I have lost interest in my appearance**	Tick	
	Definitely		3
	I don't take as much care as I should		2
	I may not take quite as much care		1
	I take just as much care as ever		0

A	**I feel restless as I have to be on the move**	Tick	
	Very much indeed		3
	Quite a lot		2
	Not very much		1
	Not at all		0

D	**I look forward with enjoyment to things:**		
	As much as I ever did		0
	Rather less than I used to		1
	Definitely less than I used to		2
	Hardly at all		3

A	**I get sudden feelings of panic:**	Tick	
	Very often indeed		3
	Quite often		2
	Not very often		1
	Not at all		0

D	**I can enjoy a good book or radio or TV program:**	Tick	
	Often		0
	Sometimes		1
	Not often		2
	Very seldom		3

Appendix 26
Norman Corah's Dental Questionnaire

Please indicate how you feel towards the dentist by circling the answer that best represents you**.**

1. **If you had to go to the dentist tomorrow for a check-up, how would you feel about it?**

a. I would look forward to it as a reasonably enjoyable experience.
b. I wouldn't care one way or the other.
c. I would be a little uneasy about it.
d. I would be afraid that it would be unpleasant and painful.
e. I would be very frightened of what the dentist would do.

2. **When you are waiting in the dentist's office for your turn in the chair, how do you feel?**

a. Relaxed.
b. A little uneasy.
c. Tense.
d. Anxious.
e. So anxious that I sometimes break out in a sweat or almost feel physically sick.

3. **When you are in the dentist's chair waiting while the dentist gets the drill ready to begin working on your teeth, how do you feel?**

a. Relaxed.
b. A little uneasy.
c. Tense.
d. Anxious.
e. So anxious that I sometimes break out in a sweat or almost feel physically sick.

4. **Imagine you are in the dentist's chair to have your teeth cleaned. While you are waiting and the dentist or hygienist is getting out the instruments, which will be used to scrape your teeth around the gums, how do you feel?**

a. Relaxed.
b. A little uneasy.
c. Tense.
d. Anxious.
e. So anxious that I sometimes break out in a sweat or almost feel physically sick.

Appendix 27
Social Communication Questionnaire

1. Is she/he now able to talk using short phrases or sentences? If *no*, skip to question 8.	yes	no
2. Can you have a to and fro "conversation" with her/him that involves taking turns or building on what you have said?	yes	no
3. Has she/he ever used odd phrases or said the same thing over and over in almost exactly the same way (either phrases that she/he has heard other people use or ones that she/he has made up)?	yes	no
4. Has she/he ever used socially inappropriate questions or statements? For example, has she/he ever regularly asked personal questions or made personal comments at awkward times?	yes	no
5. Has she/he ever got her/his pronouns mixed up (e.g., saying *you* or *she/he* for *I*)?	yes	no
6. Has she/he ever used words that she/he seemed to have invented or made up her/himself; put things in odd, indirect ways; or used metaphorical ways of saying things (e.g., saying *hot rain* for *steam*)?	yes	no
7. Has she/he ever said the same thing over and over in exactly the same way or insisted that you say the same thing over and over again?	yes	no
8. Has she/he ever had things that she/he seemed to have to do in a very particular way or order or rituals that she/he insisted that you go through?	yes	no
9. Has her/his facial expression usually seemed appropriate to the particular situation, as far as you could tell?	yes	no
10. Has she/he ever used your hand like a tool or as if it were part of her/his own body (e.g., pointing with your finger, putting your hand on a doorknob to get you to open the door)?	yes	no
11. Has she/he ever had any interests that preoccupy her/him and might seem odd to other people (e.g., traffic lights, drainpipes, or timetables)?	yes	no
12. Has she/he ever seemed to be more interested in parts of a toy or an object (e.g., spinning the wheels of a car), rather than using the object as it was intended?	yes	no
13. Has she/he ever had any special interests that were *unusual* in their intensity but otherwise appropriate for her/his age and peer group (e.g., trains, dinosaurs)?	yes	no
14. Has she/he ever seemed to be *unusually* interested in the sight, feel, sound, taste, or smell of things or people?	yes	no
15. Has she/he ever had any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes?	yes	no
16. Has she/he ever had any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down?	yes	no
17. Has she/he ever injured her/himself deliberately, such as by biting her/his arm or banging her/his head?	yes	no
18. Has she/he ever had any objects (*other* than a soft toy or comfort blanket) that she/he *had* to carry around?	yes	no
19. Does she/he have any particular friends or a best friend?	yes	no

LIFETIME

Social Communication Questionnaire (SCQ™)

AutoScore™ Form

Michael Rutter, M.D., F.R.S., Anthony Bailey, M.D., Sibel Kazak Berument, Ph.D., Catherine Lord, Ph.D., and Andrew Pickles, Ph.D.

wps
Test with Confidence

Name of Subject

Date of Birth

Date of Interview

Chronological Age _____ F _____ M Gender

Name of Respondent

Relation to Subject

Clinician Name

School/Clinic

Directions

Thank you for taking the time to complete this questionnaire. Please answer each question by circling *yes* or *no*. A few questions ask about several related types of behavior; please circle *yes* if *any* of these behaviors have ever been present. Although you may be uncertain about whether some behaviors were ever present or not, please answer *yes* or *no* to every question on the basis of what you think.

Additional copies of this form (W-381B) may be purchased from WPS. Please contact us at **800.648.8857** or **www.wpspublish.com**.

W-381B

For the following behaviors, please focus on the time period between the child's fourth and fifth birthdays. You may find it easier to remember how things were at that time by focusing on key events, such as starting school, moving house, Christmastime, or other specific events that are particularly memorable for you as a family. If your child is not yet 4 years old, please consider her or his behavior in the past 12 months.

20. When she/he was 4 to 5, did she/he ever talk with you just to be friendly (rather than to get something)? ..... yes no

21. When she/he was 4 to 5, did she/he ever *spontaneously* copy you (or other people) or what you were doing (such as vacuuming, gardening, or mending things)? ..... yes no

22. When she/he was 4 to 5, did she/he ever spontaneously point at things around her/him just to show you things (not because she/he wanted them)? ..... yes no

23. When she/he was 4 to 5, did she/he ever use gestures, other than pointing or pulling your hand, to let you know what she/he wanted? ..... yes no

24. When she/he was 4 to 5, did she/he nod her/his head to mean *yes*? ..... yes no

25. When she/he was 4 to 5, did she/he shake her/his head to mean *no*? ..... yes no

26. When she/he was 4 to 5, did she/he usually look at you directly in the face when doing things with you or talking with you? ..... yes no

27. When she/he was 4 to 5, did she/he smile back if someone smiled at her/him? ..... yes no

28. When she/he was 4 to 5, did she/he ever show you things that interested her/him to engage your attention? ..... yes no

29. When she/he was 4 to 5, did she/he ever offer to share things other than food with you? ..... yes no

30. When she/he was 4 to 5, did she/he ever seem to want you to join in her/his enjoyment of something? ..... yes no

31. When she/he was 4 to 5, did she/he ever try to comfort you if you were sad or hurt? ..... yes no

32. When she/he was 4 to 5, when she/he wanted something or wanted help, did she/he look at you and use gestures with sounds or words to get your attention? ..... yes no

33. When she/he was 4 to 5, did she/he show a normal range of facial expressions? ..... yes no

34. When she/he was 4 to 5, did she/he ever spontaneously join in and try to copy the actions in social games, such as *The Mulberry Bush* or *London Bridge Is Falling Down*? ..... yes no

35. When she/he was 4 to 5, did she/he play any pretend or make-believe games? ..... yes no

36. When she/he was 4 to 5, did she/he seem interested in other children of approximately the same age whom she/he did not know? ..... yes no

37. When she/he was 4 to 5, did she/he respond positively when another child approached her/him? ..... yes no

38. When she/he was 4 to 5, if you came into a room and started talking to her/him without calling her/his name, did she/he usually look up and pay attention to you? ..... yes no

39. When she/he was 4 to 5, did she/he ever play imaginative games with another child in such a way that you could tell that they each understood what the other was pretending? ..... yes no

40. When she/he was 4 to 5, did she/he play cooperatively in games that required joining in with a group of other children, such as hide-and-seek or ball games? ..... yes no

Appendix 28

Ethical Approvals

Ethics approval for the First Qualitative Study

From: Philip T. Smith [mailto:p.t.smith@reading.ac.uk]

Sent: 05 November 2013 14:06

To: f.j.knott@reading.ac.uk

Cc: l.a.forrest@reading.ac.uk

Subject: 2013/134/FK

Dear Fiona

Ethics proposal: The investigation of dental fear and anxiety individuals with ASD.

I was asked to look at this proposal. This proposal is in line with University of Reading ethics guidelines, and may proceed.

Regards

Philip

Ethics approval for the Second Qualitative Study

From: Eugene McSorley [mailto:e.mcsorley@reading.ac.uk]

Sent: 16 December 2015 15:02

To: f.j.knott@reading.ac.uk

Cc: PCLS Ethics

Subject: Re: 2015-175-FK - Dentists' views of dental fear and anxiety in children with Autism Spectrum Disorders

Hi Fiona

I have read the ethics app for this study and I'm happy for it proceed

Cheers

Eugen

Ethics Approval for the Third Quantitative Study

From: Philip T. Smith [p.t.smith@reading.ac.uk]

Sent: 19 August 2014 12:00

To: f.j.knott@reading.ac.uk

Cc: Louise Forrest

Subject: Ethics 2014/080/FK

Dear Fiona

Ethics proposal: The investigation of dental fear and anxiety in individuals with ASD and Typical Development

I have been asked to look at this proposal. This project is in line with University of Reading ethics guidelines, and may proceed.

Although I don't need to look at it again, there were some small points which you should attend to and correct in the hard copy Louise holds.

Regards

Philip