EXPLORING EXPERIENCES OF MOTHERHOOD: MOTHERS' ANGST, LOVE AND RESILIENCE

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DECLARATION

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PREFACE

My portfolio evolved from my interest in the role of motherhood and what the experience of motherhood may mean for women. Being a mother of three young children, over the period of the course I have begun to think more about the identity of motherhood, my own expectations, challenges and fulfilment. In my placements at both a GP surgery and at CAMHS my interest in mothers' experiences developed further, and I began to reflect on mothers' beliefs about the expectations of motherhood, and what the transition to motherhood might mean for these women.

My portfolio consists of three sections, with the theme of motherhood linking them together. The first section presents my research study which explores how mothers make sense of the experience of parenting their child with autism and anxiety; the second section consists of a journal article to be submitted to the Journal in Qualitative Health Research, and the third section presents my case study/process report which explores a mother's low self-esteem using a cognitive behavioural approach.

I became motivated to do my research when speaking to a mother with a child with autism spectrum disorder (ASD) who had managed well at primary school, but become highly anxious at secondary school, becoming hospitalised in the process. I have always had an affinity with working with autistic children, and begun to reflect on how the transition to secondary school may have triggered this high anxiety, and how it might have been for the mother to experience this. I begun to consider why this child was able to manage well in primary school and experienced such anxiety in the transition to secondary school. In the first year of the Doctorate course, I began to research the topic of anxiety and autism and the ways in which anxiety was treated in autistic children. It seemed that some autistic children experienced significant levels of anxiety, whilst others did not. In

my reading around the topic, research suggested that it was unclear how to best treat anxiety in autistic children, with CBT providing some promising results (eg. Reaven et al., 2015).

The research on anxiety and autism was largely quantitative and there was little research on the mothers' experiences of their child's autism and anxiety. The qualitative research on mothers' experiences was varied, but there seemed to be a gap in the research focussing on the anxiety and what this might mean for the mother. This took me back to thinking about my initial conversation with the mother and how she had experienced her son's anxiety. Given the importance of a mother's role in caring for her autistic child, it seemed relevant to increase our understanding and knowledge of anxiety in autism through the mother's eyes. As a counselling psychologist in training at CAMHS, I felt this would be invaluable in helping me to understand the experience of mothers and offer insight into how I could further develop my own practice and ways of working with families with autism.

I chose to use Interpretative Phenomenological Analysis (IPA) as this methodology was the most appropriate methodology to understand the subjective experience of the participant. In my reading around IPA, I was particularly drawn to the idea of reflexivity, and the notion of being able to reflect and take account of one's own experience in order to be able to fully appreciate and understand the essence of another person's experience (Smith, Flowers & Larkin, 2009). The process of reflexivity seemed to me to also be at the heart of my work as a counselling psychologist. I felt that an integral part of the training and my clinical work was to increase my own understanding and awareness through the process of reflexivity in order to be able to interpret and gain insight into the experiences of others. This seemed to mirror the way in which I would

carry out my research using IPA. IPA would enable me to focus on understanding the subjective experience of the mothers, and interpret the meaning of their experiences. The process of reflexivity would enable me to reflect on the ways in which my own experiences may impact on the interpretation and to take account of this. Becoming more aware of my own assumptions would be a challenge, and one that I felt would be of benefit in both my research and clinical work.

The second section of the portfolio consists of a journal article to be submitted to the Journal of Qualitative Health Research. I specifically chose to summarise my research into a journal article as I felt that there is such little research addressing mothers' experiences of anxiety in their autistic child, that I wanted the opportunity to present my research in the form of a journal article in the hope that it may reach a wider audience. I chose this journal as it has published similar articles to my qualitative research on experiences of caregivers in autism. I hope that my research may be of interest to the journal, and may offer some new insight into the experiences of mothers of children with autism and anxiety.

The final section of my portfolio is my case study/ process report titled "Exploring a client's low self-esteem using a cognitive behavioural approach". I chose this case to present, as the piece consisted of working with a young mother who had become increasingly low in confidence and self-esteem since having her two daughters. Working with this mother highlighted to me the importance of being reflexive in my work as a counselling psychologist as I became increasingly aware of my own thoughts and feelings of motherhood and the need to take account of my own experiences. This was a steep learning curve for me, and whilst empathising with this young mother, I had to work hard

in supervision and my own therapy to ensure that my experiences did not impinge upon the therapeutic work with this client. The work was also different to that of my work with mothers at CAMHS, which largely focused on the child rather than working with the mother's own issues. This case gave me the opportunity to work closely with the mother about her experiences of motherhood, the focus being to improve her low self-esteem to give herself permission to take a break from her children, and to allow family members to develop closer relationships with her daughters. Much of my work at my placements was integrative, and this case enabled me to work within a CBT framework and experience the ways in which specific CBT interventions could be helpful for this client.

The work in this portfolio feels aligned to the way in which I endeavour to practice as a counselling psychologist. In my research, I have tried at all times to understand the subjective experience of the participant, and am aware that my interpretations are of a subjective nature, the reader may make their own interpretations of the material. As a counselling psychologist, I align myself with the humanistic-phenomenological approach, which fits with my use of IPA. My approach is influenced by pluralism, and I believe that there are multiple ways of working with people at different points in time, thus I work integratively with clients focusing on their needs and goals. I hope my portfolio represents the way in which I have endeavoured to focus on understanding the subjective experiences of both participants and clients, whilst engaging in the process of reflexivity to try to be aware of my own assumptions that may influence my interpretation of the underlying meaning and essence of their experiences.

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PART ONE: RESEARCH

"I USED TO FEEL LIKE I WAS UNDER HOUSE ARREST":

MOTHERS' EXPERIENCES IN CARING FOR THEIR CHILD

WITH AUTISM AND ANXIETY

ABSTRACT

This study explored how mothers make sense of the experience of parenting their child with autism and anxiety in order to inform the development of future intervention for anxiety in children with autism spectrum disorder (ASD). Using the method of Interpretative phenomenological analysis (IPA), seven mothers of autistic boys aged between 10-16 years were interviewed. IPA was used to understand and gain insight into the mothers' subjective experience of their autistic child's anxiety and the meaning that this experience had for them. The findings consisted of three master themes: mothers' internal struggle, loss of self and overwhelming sense of tensions. The findings highlighted the emotional stress, anxiety and exhaustion that these mothers experienced in relation to managing their child's anxiety. Their sense of helplessness and inner turmoil was evident in the ways in which they adapted their lives to accommodate their child's needs. The findings suggest the need to consider the mothers' emotional well-being together with those of her child when working with families with autism. Implications for counselling psychology together with suggestions for future research are discussed.

CHAPTER ONE: LITERATURE REVIEW

1.1 INTRODUCTION

This study aims to explore how mothers make sense of the experience of parenting their child with autism and anxiety. This study is specifically interested in understanding and gaining insight into the mothers' experiences of their autistic child's anxiety in order to inform the development of future intervention for anxiety in children with autism spectrum disorder (ASD). The aim of this literature review is to provide a review of the relevant literature on autism and anxiety in support of the rationale and context from which this research has developed.

1.1.1 Rationale for study

It is currently estimated that 1 in 88 youth are now diagnosed with ASD (Centres for Disease Control and Prevention, 2012) with approximately 70% of individuals with ASD experiencing at least one comorbid disorder, the most common being anxiety (White, Oswald, Ollendick & Scahill, 2009). In clinical settings anxiety related concerns are among the most common presenting problems for school age children and adolescents with ASD (Ghaziuddin, 2002).

The literature suggests that parents of children with ASD experience greater stress than parents of typically developing children or parents of children with other developmental disabilities (Kuhn & Carter, 2006). Research suggests that the impact of anxiety on children with ASD may result in an increase in behavioural problems (eg Joliffe, Landsdown & Robinson, 1992; Kim, Szatmari, Bryson, Streiner & Wilson, 2000), and that it is often these behavioural problems

that parents find the most difficult and stressful to manage (eg Estes et al., 2009).

Research suggests that parental involvement in the treatment of anxiety in children with autism may be beneficial (eg. Reaven & Hepburn, 2006) but that parental stress may reduce the success of outcomes in treatment (eg. Rao & Beidel, 2009). Furthermore, it is currently unclear as to what intervention is the most effective in treating anxiety in children with ASD, with cognitive behavioural therapy (CBT) showing some promising results in reducing anxiety in children with autism (eg Reaven et al., 2015).

The research on anxiety in children with ASD has been largely quantitative in nature. In one of the few qualitative studies on parental perspectives on the nature of anxiety in children with ASD, parents reported that the impact of anxiety was often more substantial than the impact of ASD itself (Ozsivadjian, Knott and Magiati, 2012). Through the use of Interpretative Phenomenological Analysis (IPA), this study aims to further explore how mothers make sense of the experience of parenting their child with autism and anxiety in order to inform the development of future intervention of anxiety in children with ASD.

1.1.2 Overview

Chapter one in this thesis provides an overview of the literature on autism and anxiety outlining its relevance to the field of counselling psychology. Chapter two outlines a conceptual framework of IPA, the philosophical and epistemological underpinnings of IPA and the rationale for using IPA. The second part of chapter two describes the ways in which I have tried to ensure quality within my research, and the process of data collection and analysis. Chapter three outlines the findings from the study, which are grouped into three super-ordinate themes

together with their subthemes that emerged from the data. These themes are based on my own interpretations of the data, and I am aware that others may interpret the data differently. Chapter four discusses these findings in relation to the empirical research and highlights the new findings that can be added to the current body of literature. The second part of the discussion chapter focuses on the ways in which my findings can be related to theory in particular theories relevant to the field of counselling psychology. Implications for counselling psychology are discussed together with the strengths and limitations of the study and suggestions for future research.

1.2 WHAT IS AUTISM SPECTRUM DISORDER?

1.2.1 Brief history of autism

Leo Kanner (1943) first used the term "autism" in his report describing a set of symptoms displayed by a group of eleven children. In this report he described the core features of autism as being the preference for aloneness, intolerance of change (sameness), fascination with objects, impairments in the use of language and restricted interests. Hans Asperger (1944) went on to describe a group of children who he noted as having average or above average intelligence, age appropriate or beyond language skills but had limited social and motor skills and restricted interests. The term Asperger's syndrome came into use in 1981, through the work of Lorna Wing (1981) who referred to Asperger's work in her report and descriptions of other similar cases. It has been debated over the years as to whether Asperger's syndrome should be considered part of or separate from the autistic spectrum disorder.

The existence of autism was officially recognised in the DSM-III by the American Psychiatric Association (1980) and listed specific criteria to be met in order for a diagnosis to be given. The criteria consisted of early onset before 30 months of

age, pervasive lack of responsiveness to other people, gross deficits in language development, if speech is present – peculiar patterns of speech, bizarre responses to various aspects of the environment, absence of delusions, hallucinations. The need to meet all listed criteria resulted in few diagnoses being made. In 1994, the DSM-IV introduced the concept of the autism spectrum, which ranged from mild to severe symptoms. This included Asperger's syndrome. At this point, the definition of autism developed to include autistic disorder, Asperger's disorder, and pervasive developmental disorder – not otherwise specified. The criteria listed in DSM-IV consisted of three domains: marked impairment in social interaction, delayed and or deviant language development, repetitive behaviour and/or circumscribed interests. The criteria for early age of onset remained. To be diagnosed, a child needed to show two symptoms in the social domain and at least one symptom in each of the other domains. The broadening of this criteria meant that the number of children diagnosed with ASD increased (Fombonne, 2009).

1.2.2 Current DSM-5 classification

The American Psychiatric Association (2013) describes ASD as being a neurodevelopmental disorder defined by deficits in communication and social interaction, and the engagement in restricted and repetitive patterns of behaviours. The DSM-5 describes ASD as having two broad areas: deficits in social communication and social interaction, and secondly, repetitive behaviour and restricted interests (Scahill, Turin & Evans, 2014). Under the new diagnostic criteria in DSM5 the terms Asperger's syndrome (AS), autistic disorder, pervasive developmental disorder not otherwise specified will be replaced by one umbrella term autistic spectrum disorder and further distinctions will be made according to severity levels, rather than the presence of the symptom. The DSM-5 focuses on the severity in each of the domains as opposed to the

presence of symptoms. Those who have been given one of the terms under DSM-IV will still be able to use those labels if they so wish. A concern with the new criteria is that it may be more difficult for higher functioning individuals on the autistic spectrum to receive a diagnosis because of the stricter DSM5 criteria (Mattila et al., 2011; Mandy, Charman & Skuse, 2012), and may therefore not have access to the appropriate services. In their study assessing 30 patients, Worley and Matson (2012) found that one third of patients who met DSM-IV-TR diagnosis for an ASD did not meet the diagnostic criteria under DSM-V. The removal of the label of "Asperger's syndrome" may also cause concern for some individuals and their parents as they perceive that this label carries less stigma attached to it, given the requirement of normal IQ and speech (Adler, Minshawi & Erickson, 2014).

1.2.3 Prevalence

Since the introduction of DSM-IV, the prevalence of autism has risen, due to the criteria broadening and an increase in the number of children being diagnosed (Fombonne, 2009). Furthermore, research samples have been broadened to include individuals with ASD from the wider community, and are no longer just selected from samples of individuals using clinical services (Scahill, Turin & Evans, 2014). Improved assessment methods have also meant an increase in diagnosis (Scahill, Turin & Evans, 2014). ASD is now estimated to affect approximately 1 in 88 youth and about 1% of adults (Brugha et al., 2011; Centres for Disease Control and Prevention, 2012). Males are more likely than females to have autism with a ratio of 4:1 (Aarons & Gittens, 2002). Research suggests that those females with ASD are likely to experience more severe symptoms than males in the form of lower cognitive abilities (Lecavalier, 2014).

1.2.4 Aetiology

In the 1950s autism was believed to be a result of the mother's failure to nurture and bond with her child in early infancy (Scahill, Turin & Evans, 2014). In the 1970s, evidence suggested that this was not the case, and longitudinal studies posited that autism was a brain-based disorder with a genetic aetiology (Reichow, Campbell & Volkmar, 2014). Twin studies and family studies suggest that autism is heritable, and that autism is likely to be a genetic disorder (Aarons & Gittens, 2002). For example, Folstein and Rutter (1977) demonstrated that where there was a presence of autism in a family, identical and non-identical twins, and siblings were at increased risk of autism. Further research has indicated that relatives of people with autism are more susceptible to autism, and that within families where there is autism, there is a higher number of relatives with speech, learning and cognitive impairments (Aarons & Gittens, 2002).

1.2.5 Comorbidity

Evidence suggests that individuals with autism are likely to experience a range of comorbid disorders such as intellectual disability, ADHD, language disorders, psychiatric disorders such as oppositional defiant disorder (ODD) and obsessive compulsive disorder (OCD), and emotional disorders such as anxiety and depression (Tager-Flusberg & Dominick, 2011). The APA (2013) reported that approximately 70% of individuals with ASD have at least one comorbid disorder, the most common being anxiety (White et al., 2009). It may be that the comorbid disorders are independent of ASD symptoms or it may be that these conditions are associated with the core features of ASD, the severity of which are influenced by the individual's level of functioning. Szatmari and McConnell (2011) posit that comorbid anxiety can be identified by the presence of symptoms that are independent of ASD and result in additional impairment

beyond the diagnosis of ASD for the individual. However, as will be discussed later, it is likely that there is a bi-directional relationship between symptoms of anxiety and the core impairments of ASD (White et al., 2010) making it challenging to determine at what point the symptoms experienced are reflective of an additional comorbid disorder or whether they are seen to be part of the ASD.

1.2.6 Variability in Autism

The introduction of autism as a "spectrum" in the DSM IV recognised the variability of symptoms ranging from mild to severe. Factors such as developmental level, language delay, IQ, and possible comorbidity may influence the severity of symptoms experienced (Lecavalier, 2014).

Research suggests that children with autism present with high levels of behavioural problems (Brereton, Tonge & Enfield, 2006). This includes challenging behaviour such as self-harm, tantrums, aggression and destruction of property. Evidence suggests that as children with ASD become older, their ability to adapt becomes more impaired compared to their age-related peers (Kanne et al., 2011). Lecavalier (2006) reported that children with increasingly impaired adaptive skills experienced significantly greater behavioural problems. Estes, Dawson, Sterling & Munson (2007) explored the relationship between behavioural problems and the level of functioning in a sample of 6-9 year olds. Their results suggested that children with higher functioning ability at age 6 displayed greater internalising symptoms, such as symptoms of anxiety/depression, by age 9, in contrast to children who were described as being lower functioning. These children displayed greater hyperactivity, irritation and attention problems by age 9, suggesting that the level of intellectual

functioning may be associated with different patterns of behavioural symptoms as the child increases in age.

1.2.7 Intervention

The variability in symptoms present in ASD together with the common presence of comorbid disorders means that any intervention needs to be tailored to the individual child's needs (Suh & Fein, 2014). These authors suggest that it is the presenting symptoms, skills, behaviours and difficulties that need to determine the appropriate treatment for each child. Furthermore, they suggest psychiatric disorders such as anxiety, depression, sleep disturbance may mean that the individual is unable to access treatment appropriate for some of the core features of autism and these may need to be addressed first so that further intervention may be successful.

Evidence suggests that early intensive behavioural intervention (EIBI) has become known to be the most empirically based treatment for ASD (Najdowski, Gould, Lanagan & Bishop, 2014). Studies have shown that EIBI leads to improvements in intellectual, communicative and adaptive functioning in individuals with ASD (eg Peters-Scheffer, Didden, Korzilius & Sturmey, 2011; Reichow & Wolery, 2009). Research suggests that early intervention together with factors such as higher cognitive and language abilities in early childhood is likely to result in optimal outcomes (Helt et al., 2008). The absence of intellectual disability and language delay, have been associated with greater improvement over time (Baghdadli et al., 2007). In their review of the literature to suggest guidelines for recommended practice in early intervention for children with autism, Roberts and Prior (2006) concluded that the optimal age for commencement of treatment was between two and four years, as this period of time is critical for learning and may influence the way in which the child later

develops. The authors also concluded that the intervention needed to be intensive in order to be successful and that the programmes should be tailored to meet the child's and family's needs. Given that there is no cure for autism, there needs to be a realism about what the individual may achieve through treatment, the focus of the intervention being to help the autistic individual and their family to manage and adapt to the autism in the most effective way possible (Volkmar, Paul, Klin & Cohen 2005).

1.3 ANXIETY DISORDERS

1.3.1 What is an anxiety disorder?

The American Psychiatric Association (APA) (2013) describes anxiety as an emotion in which an individual experiences feelings of tension, worried thoughts and physical changes. The *DSM-5* describes a variety of anxiety disorders that may be experienced by both adults and children across the lifespan. Anxiety disorders include separation anxiety disorder, selective mutism, specific phobia, social anxiety disorder, panic disorder, agoraphobia and generalised anxiety disorder. Epidemological research has reported the prevalence of anxiety disorders in children and adolescents as being between 2-27%, and anxiety disorders are said to be the most common disorders experienced by children and adolescents (Cartwright-Hatton, McNicol & Doubleday, 2006). Anxiety disorders in childhood often have overlapping symptoms and are likely to be comorbid with one another (Kendall et al., 2010; Russo & Beidel, 1994).

1.3.2 Assessment

Assessing anxiety in childhood is a complex process, particularly given the high rate of comorbidity with depression and other externalising disorders (Brady & Kendall, 1992). Anxiety in youth is also said to be a normal phenomenon depending on the developmental stage of the child (Marks, 1987). It is only

when the anxiety is such that it is considered to impair on the child's ability to function that the diagnosis of an anxiety disorder may be appropriate (Muris, 2014). Anxiety is often assessed using multiple methods such as diagnostic interviews, rating scales and from care providers (Achenbach, McConaughty & Howell, 1987). Diagnostic interviews using structured or semi-structured interviews are commonly used to identify symptoms of anxiety in youth. They may also be used to assess the extent to which the treatment has been effective (Seligman, Swedish, Flannery-Schroeder, 2014). Rating scales are used to aid the identification of the severity of symptoms and to assess treatment outcome (Seligman, Ollendick, Langley & Baldacci, 2004). More recently the emphasis has shifted from a focus on the symptoms to focusing on understanding and exploring the underlying processes which may be causing and maintaining the anxiety disorders in childhood (Seligman et al., 2014).

1.3.3 Aetiology of anxiety

Research suggests that anxiety disorders may be a result of multiple factors and the DSM-5 reports that there are three distinct factors that may result in the development of an anxiety disorder. These are considered to be temperamental, environmental, and genetic/physiological.

1.3.3.1 Temperamental factors

Research suggests that a predisposing factor of anxiety may be the presence of negative emotionality or "neuroticism" (Eysenck & Eysenck, 1985). "Neuroticism" is said to be a temperamental trait that makes some individuals more prone to experience negative emotions. "Extraversion" is another temperamental trait which has been thought to be significant in the aetiology of anxiety. Eysenck and Eysenck (1985) suggest that those individuals who tend to experience low extraversion, may be more likely to display avoidant type

behaviours which could then result in the development of some anxiety disorders. Individuals who are predisposed to both neuroticism and extraversion may be at greater risk for developing an anxiety disorder (Muris & Ollendick, 2005).

1.3.3.2 Environmental risk

Research suggests that the parent-child relationship may play a role in the onset of anxiety disorders. Attachment theory suggests that the type of attachment a child may have with his parent or caregiver may be a predictive factor in the onset of anxiety disorders. Warren, Huston, Egelanc & Sroufe (1997) suggested that those children who appeared to have an insecure attachment style were more likely to develop an anxiety disorder later in life compared with those who were considered to be securely attached.

Parenting behaviours such as frequent criticism, and less warmth, have been shown to play a role in the development of anxiety in typically developing children (Creswell, Schiniering & Rapee, 2005; Rapee, Schniering & Hudson, 2009). In a review of the parenting literature, Rapee (1997) suggested that parental overprotection and control may be more consistently associated with the anxiety disorders, with parental overprotection highlighted as a key factor in the development of anxiety in children (Hudson & Rapee, 2004; Chorpita & Barlow, 1998). A main limitation in the research is that it is unknown whether the anxiety in the child may result in over protective parenting or whether the over protective parenting style may lead to child anxiety (Rapee et al., 2009). Muris (2014) suggests that parents with this parenting style may experience anxiety themselves, and may be trying to protect their child from experiencing possible distress. This may result in children's worries being exacerbated by their parents

over protectiveness, reducing their perceived control in the situation and increasing their anxiety and avoidance behaviour.

Stressful life events such as death in the family, being bullied, transition to a new school, learning difficulties and parents' psychiatric problems may contribute to the development of anxiety disorders in youth, in particular generalised anxiety disorder and separation anxiety disorder (Tiet et al., 2001).

1.3.3.3 Genetic and physiological vulnerability

Studies suggest that genetics play a contributory role to the development of anxiety disorders in childhood. In their qualitative overview of the literature, Eley and Gregory (2004) reported that the genetic influence accounted for about 30% of anxiety disorders in youth. Research has also suggested that the amygdala may play a role in the development of anxiety and that youth who are susceptible to anxiety may have hyperexcitable subcortical brain circuits which promote anxiety (Blackford & Pine, 2012), and heightened amygdala sensitivity (Grillon, Dierker & Merikangas, 1997).

1.3.4 Maintaining variables

The cognitive-behavioural model of anxiety (eg Clark & Wells, 1995) suggests that anxiety may be maintained by a variety of influences, such as our maladaptive thoughts, our physical reactions and avoidance behaviour. Our negative thinking patterns may result in the experience of physiological symptoms such as increased heart rate and sweating, which leads the individual to avoid the feared situation or stimulus. Through cognitive distortions and avoidance behaviour, the cycle is maintained, the individual not having the opportunity to be exposed to their feared situation or stimulus (Muris & Field, 2008; Kennerley, 2014).

1.3.5 Intervention for anxiety disorders in typically developing youth

Evidence suggests that Cognitive Behavioural therapy (CBT) is the most effective form of psychological intervention for children and adolescents experiencing anxiety disorders (eg March, 2009; Seligman & Ollendick, 2011). CBT includes interventions such as psychoeducation, exposure, cognitive restructuring, parent training or parent psychoeducation, relaxation, modelling and self monitoring (Rotherham-Borus, Swendeman & Chorpita, 2012). Some research suggests that the inclusion of parents in a CBT programme leads to a more successful outcome for the child, particularly when parents experience anxiety problems themselves (eg. Cobham, Dadds & Spence, 1998). Given that family factors may contribute to the child's anxiety, inclusion of parents in the treatment programme is believed to be an important part of the intervention (Muris, 2014). However, some studies have found that parental inclusion in the CBT intervention does not always improve the efficacy of the outcome of treatment (eg. Bodden et al., 2008) and this continues to be explored.

1.4 ANXIETY AND ASD

1.4.1 Prevalence

White et al., (2009) reviewed 40 papers published between 1990 and 2008 on anxiety in children and adolescents with autism spectrum disorders (eg. Kim et al., 2000; Bellini, 2004). They found the range of children with ASD experiencing some form of impairing anxiety to be between 11% and 84%. Some of the most common anxiety disorders reported in children with ASD were simple phobias, generalised anxiety disorder, separation anxiety disorder, obsessive-compulsive disorder, and social phobia. Research comparing the rate of anxiety in typically developing youth to other groups of youth, suggest that children with ASD experience more anxiety difficulties than neuro-typical children, or children with

learning difficulties, language impairments, Down syndrome and Williams syndrome (Gadow, DeVincent, Pomeroy & Azizian, 2005).

The range in prevalence could partly be explained by the ways in which studies assessed anxiety, such as the use of informant report measures and semi - structured diagnostic interviews, and the different use of sampling methods (White et al., 2009). Informant measures rely on others to describe the individual's behaviour and may lead to inaccuracies, and self-report measures may be unreliable due to the individual's difficulty to report their symptoms and emotions (Kerns & Kendall, 2014). Some studies used clinical based samples and others used community based samples. Within community samples, studies estimate the prevalence of anxiety within ASD to be between 40-50% (Leyfer et al., 2006).

The range in prevalence could also be explained by differences in subgroups of ASD. Research suggests that age and level of functioning may play a role in severity of anxious symptoms. For example, studies have shown that individuals who are higher functioning, experience a greater level of anxiety than those with a lower functioning ability (Lecavalier, 2006; White et al., 2009). Adolescents with Asperger's syndrome (AS) have been found to present with high levels of anxiety (Attwood, 1998; Kim et al., 2000; Farrugia & Hudson, 2006) and common comorbid problems in the AS population include emotional disorders such as anxiety and depression (Ghaziuddin, Weidmer, & Ghaziouddin, 1998). Other studies suggest that according to parent report, younger children as well as children with more intellectual impairments may experience milder anxiety symptoms, compared with children who are older and higher functioning (Farrugia & Hudson, 2006; White et al., 2009). This may be due to older and higher functioning children becoming more anxious as a result of their increased

awareness of their difficulties (Kuusikko et al., 2008). This will be discussed in more detail further on in this chapter.

1.4.2 Assessment of anxiety with ASD

Diagnosing anxiety in ASD can be particularly challenging given the overlap of symptoms with core features of ASD (Wood & Gadow, 2010). For example, social and communication impairments and ritualistic behaviour are areas in which there is likely to be significant overlap (Kerns & Kendall, 2014). Furthermore, anxiety measures used to determine symptoms of anxiety in those with ASD have been largely developed for individuals without ASD. The measures do not therefore necessarily consider the full range of anxiety symptoms that may be experienced in ASD (Kerns & Kendall, 2014). Anxiety within ASD can be difficult to diagnose as a result of the social and communication impairments in ASD, which may limit the individual's ability to self report their thoughts, emotional and physiological states (Myers & Johnson, 2007). Thus, the use of semi-structured interviews to assess anxiety may present a challenge, as individuals with ASD may be unable to fully communicate their emotions (Scahill, 2012).

To assess anxiety symptoms in ASD, Hagopian and Jennett (2014) suggest that a multimodal assessment needs to be carried out. This includes observing behaviour, emotion, physiological responses, and gathers information from carers and from the individual (MacNeil, Lopes & Minnes, 2009). Given that the relationship between individuals with ASD and their parents or carers is more dependent than that of typically developing individuals (Shattuck et al., 2012) parental and other's reports of the child's behaviour should be included. Hagopian and Jennett (2014) posit that it needs to be determined whether presenting symptoms are as a result of anxious avoidance (anxiety) or

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representative of simple avoidance (avoidance of non preferred stimuli and not necessarily representative of an anxiety disorder). These authors suggest given the variability within ASD, that the individual's skills, level of functioning and impairment needs to be considered when assessing the symptoms of anxiety.

Furthermore the parent-child interaction should be taken into consideration when assessing anxiety. Parental anxiety, or low tolerance to their child's anxiety may result in the child's avoidant behaviour being inadvertently reinforced as the parent tries to reduce their child's anxiety. Thus understanding the context of the parent-child relationship and interaction may help to gain greater insight into the mechanisms underlying the child's anxiety and help to inform treatment for the child, together with increasing adherence to the suggested recommendations (Hagopian & Jennett, 2014; Reaven & Hepburn, 2006).

1.4.3 Presentation of anxiety in ASD

Studies suggest that individuals with ASD experience higher rates of anxiety than the rest of the population (Magiati, Ozsivadjian, & Kerns, 2017). However, not all individuals with ASD experience clinically significant anxiety symptoms, and it has been noted that individuals with ASD may present with different anxiety symptoms to those of typically developing individuals with anxiety.

There have been only a few qualitative studies exploring anxiety in individuals with ASD. Ozsivadjian et al., (2012) used focus groups with mothers of cognitively able children aged between 7-18 years old. Carers identified triggers of anxiety as being those of the more common sources of anxiety such as worries about social situations, worries about not being able to meet expectations, together with atypical ASD-related triggers such as changes in

routine, difficulties understanding social cues, anxiety around too much sensory stimulation and not being allowed to engage in repetitive behaviour or preferred interests. The ways in which the anxiety manifested itself included typical presentations such as avoidance, use of safety behaviours, and more ASD-related behaviour which were described as being increases in sensory, repetitive behaviours and socially inappropriate behaviour such as giggling when anxious. Magiati et al., (2016) and Trembath, Germano, Johanson and Dissanayake (2012) found similar results, with anxiety presented in both typical and atypical ASD related ways. ASD related manifestation included increases in challenging and repetitive behaviour. Bearss et al., (2016) used focus groups of caregivers of 3-17 year old children with ASD and explored how anxiety presents itself in their children. The authors identified triggers such as being separated in a crowd, misinterpretation of situations, academic expectations and being teased. ASD related triggers included sensitivity to certain sensory stimuli, changes to routine and other's not following rules. These studies suggest that individuals with ASD experience anxiety in both typical and atypical ASD related ways (Magiati et al., 2017).

Findings from quantitative studies further support the above findings and suggest that individuals with ASD present anxiety in both typical and atypical ways. Kerns et al., (2014) found that 31% of participants presented with both typical and atypical ASD related anxiety symptoms, 17% with typical DSM anxiety disorders only and 15% with ASD related symptoms of anxiety only. Atypical anxiety was related to changes in routine, social fears, prevention of performing ritualistic behaviours and unusual specific fears. White et al., (2015) further support these results and their study suggests that symptoms of anxiety may be expressed differently in individuals with ASD and that traditional ways in

which anxiety is measured may not necessarily take account of these
differences.

The following two sections focus on the presentation of social anxiety disorder
(SAD) and obsessive compulsive disorder (OCD) in individuals with ASD.
Although OCD is no longer classified as an anxiety disorder in the DSM-5
anxiety disorders, it has been explored in studies of anxiety and ASD prior to the
DSM-5 in 2013. These two anxiety disorders will be discussed in greater detail
due to similarities and overlap in their symptomatology with symptoms of ASD.

1.4.4 Social anxiety disorder (SAD) or ASD?

As discussed it is not always clear whether symptoms of anxiety in an individual
with ASD are representative of a core feature of ASD or are indicative of a
comorbid anxiety disorder. One of the core impairments of ASD defined in the
DSM-5 is that of social and communicative impairment. Thus individuals with
ASD have difficulty with social and emotional reciprocity and may find it difficult
to develop and sustain relationships with others (Mazefsky & Herrington, 2014).
Magiati et al., (2017) suggest that social anxiety in individuals with ASD may be
different to the way in which social anxiety manifests in typically developing
individuals in that an individual with ASD may experience symptoms of social
anxiety without the fear of negative evaluation. The cognitive behavioural model
of social anxiety (Clark & Wells, 1995) suggests that negative evaluation refers
to an individual's beliefs that he/she will be unable to meet others standards for
approval, thus resulting in being negatively thought upon. ASD related social
anxiety may be more related to difficulties in understanding social situations,
and worries about causing offence as a result of not understanding social
etiquette (Gillot, Furniss, & Walter, 2001).

Wood and Gadow (2010) suggest that an individual with ASD may find social encounters anxiety provoking and overwhelming. This in itself may lead to the onset of social anxiety in individuals with ASD. Research suggests that as a result of the difficulties in understanding other's perspectives, emotions, and non-verbal communication, individuals with ASD may become increasingly anxious (eg Harms, Martin, & Wallace, 2010). For those individuals with ASD who are socially motivated and want to form friendships, this can be even more anxiety provoking (Bauminger & Kasari, 2000). Furthermore, research suggests that up to 70% of children with ASD experience being bullied, and parents rated their children who were thought to be bullied at least once a week as having significantly more anxiety than those children with ASD who reported no or less frequent experiences of being bullied (Cappadocia, Weiss, & Pepler, 2012).

The DSM-5's definition of SAD now includes ASD as one of the common comorbid disorders. White, Schry and Kreiser (2014) argue that it is important to identify SAD as a comorbid disorder as they suggest that not everyone with ASD experiences symptoms of social anxiety. They suggest that social anxiety may further impair the core feature of social communication impairments within ASD. If not diagnosed, White et al., (2014) argue that the interventions aimed at improving social deficits in individuals with ASD may be less successful and lead to the development of additional problems such as avoidance of school, or poor academic performance.

Research suggests that SAD is the most commonly occurring anxiety disorder in individuals with ASD (Kuusikko et al., 2008) with approximately 17-22% of individuals with ASD experiencing symptoms that would meet the benchmark for a social anxiety disorder. Evidence suggests, however, that social anxiety is not a comorbid disorder experienced by all individuals with ASD. The research on

the presence of anxiety symptoms in individuals with ASD has suggested that nearly half (49%) of adolescents with high functioning autism present with symptoms of social anxiety at the level considered to be representative of a social anxiety disorder (Bellini, 2004). Adolescents with ASD are at greater risk of SAD than typically developing teenagers, the prevalence among neuro-typical teenagers being approximately 9% (Burstein et al., 2011). Within community samples, the prevalence of social anxiety present in adolescents with ASD has been found to be approximately 10.7 – 29.2% (Leyfer et al., 2006, Simonoff et al., 2008). This is said to rise for adolescents in clinical samples to nearly half of adolescents experiencing symptoms of social anxiety (Kuusikko et al., 2008).

Anxiety problems can have a serious impact on individuals with ASD (Greig & Mackay, 2005) impacting on their school performance, peer relationships and family functioning (Bellini, 2004; Sze & Wood, 2007). Adolescence can be a particularly difficult period for individuals with ASD as they may become more aware of their social deficits and limitations in interacting with others. If a child has a co-occurring social anxiety disorder, it could lead to further avoidance of social situations, awkward interactions with peers and difficulties in developing meaningful social relationships (Bellini, 2006). This could intensify the symptoms already experienced as part of the AS and lead to an escalation of emotional and behavioural problems.

White et al., (2010) suggest that there is likely to be a bi-directional relationship between social impairment and social anxiety in individuals with ASD. The more anxious a person with ASD becomes in a social situation, may result in increased avoidance of the situation, and lead to fewer opportunities to interact with peers. This, in turn, increases the social and communication impairments, there being less opportunities to practice social skills (eg Joseph, Ehrman,

McNally & Keehn, 2008), thus increasing the presence of social anxiety. Kuusikko et al., (2008) examined social anxiety in children and adolescents with high functioning autism (HFA) and Asperger's syndrome (AS). As children with HFA /AS grew older they experienced increasing symptoms of social anxiety, whereas typically developing children reported a decrease of symptoms of social and evaluative anxiety. Adolescents with HFA/AS reported more behavioural avoidance and generalized social anxiety symptoms than did normally developing children. Furthermore, research suggests that social anxiety leads to increased problems of loneliness (White and Roberson-Nay, 2009), aggression (Pugliese, White, White & Ollendick, 2013) and hostility (White, Kreiser, Pugliese, & Scarpa, 2012) amongst individuals with ASD.

Studies suggest that higher functioning individuals with ASD are more likely to experience social anxiety than lower functioning individuals. This may be due to higher functioning individuals having greater awareness and insight of their difficulties in social communication together with their increased desire for friendships (Kuusikko et al., 2008; Sukhodolsky et al., 2008). Williamson, Craig & Slinger (2008) found that adolescents with HFA placed as much value as neuro-typical adolescents regarding the desire for friendships and peer approval, at the same time perceiving themselves as having less approval from their peers and less socially able. Social anxiety is likely to increase with age, as the adolescent becomes more aware of their social difficulties, and their desire for social friendships may also increase (Bellini, 2004). The individual's social motivation also affects the likelihood of experiencing social anxiety, with those who are socially motivated being at greater risk of experiencing social anxiety than those who do not desire social relationships (Klin, Jones, Schultz & Volkmar, 2003).

Research has indicated that the anxiety experienced by children and adolescents with ASD may underlie some of the behavioural problems they exhibit. Kim et al., (2000) studied the prevalence of anxiety and mood problems among children with autism and AS. They found children with AS and autism demonstrated a higher level of depression and anxiety than that of the community sample. They were found to be more aggressive, had worse relationships with teachers, peers and family members and their behaviour impacted on their parents social lives. Adolescents with AS have been found to experience high levels of anxiety equivalent to those adolescents with anxiety disorders and significantly higher than the adolescents in the general population (Farrugia & Hudson, 2006). These results support other findings which indicate that adolescents with AS present with significantly higher internalising problems such as anxiety which may be an underlying cause of a child's problematic external behaviours such as aggression and tantrums (Joliffe et al., 1992). The literature suggests that the impact of anxiety on children and adolescents with ASD tends to increase with age, cognitive functioning and may manifest itself through emotional and behavioural problems. This may impact on many areas of the child's life such as peer interactions, schooling and overall family functioning.

1.4.5 Obsessive compulsive disorder (OCD) or ASD?

As previously mentioned, the DSM-5 describes ASD as having two broad domains: deficits in social communication and social interaction, and secondly, repetitive behaviour and restricted interests. Individuals with ASD are likely to display restricted and repetitive behaviours in the form of restricted interests, fixations on certain objects and rigid routines, and stereotyped motor movements. Research suggests that the frequency of these behaviours are associated with the degree of functional impairment (South, Ozonoff, &

McMahon, 2005). Individuals with ASD may become fixated on particular interests, and may have a desire for sameness, being rigid with certain schedules and inflexible to changes in routine (Militerni, Bravaccio, Falco, Fico & Palermo, 2002).

OCD is "characterised by the presence of recurrent obsessions and /or compulsions that take more than one hour per day" (American Psychiatric Association, 2013). OCD affects approximately 1-2% of the youth, and 1% of the adult population (Kessler, Chiu, Demler & Walters, 2005). Obsessions are described as being intrusive thoughts, images or sounds, which repeatedly enter an individual's mind and are experienced as distressing (Rahman, Reid, Parks, McKay & Storch, 2011). Compulsions are described as being the behaviours carried out to reduce the anxiety or distress experienced as a result of the intrusive thoughts (Rahman et al., 2011).

1.4.5.1 Symptom overlap and difference in OCD and ASD
Research suggests that up to 37% of youth (Leyfer et al., 2006) and 25% of adults (Russell, Mataix-Cols, Anson & Murphy, 2005) with ASD experience comorbid OCD symptoms. Individuals with ASD and comorbid OCD are at greater risk of experiencing psychosocial impairment (Mack et al., 2010). Lewin, Wood, Gunderson, Murphy & Storch (2011) found that adolescents with ASD and OCD were more likely to experience separation anxiety disorder, social phobia and clinically significant hyperactive symptoms as compared to adolescents with only OCD.

Determining whether an individual's presentation of repetitive and fixated thoughts and behaviours or rituals represent that of ASD or OCD may be challenging. Obsessions in OCD and fixated interests in ASD may both involve

continuous repetitive thoughts (Wu, Rudy & Storch. 2014), and compulsions which may present as repetitive behaviours needing to be performed. These disorders may differ in the underlying motivation for carrying out the ritualistic behaviour and the extent to which distress is experienced as a result of the intrusive thoughts (Wu, Rudy & Storch, 2014). For example, within OCD, obsessions are said to cause distress, are experienced as being intrusive and are not pleasurable for the individual. In contrast, individuals with ASD often find their repetitive thoughts and fixations pleasurable and may have specific interests they like to discuss. They may repeatedly focus on these thoughts, and do not perceive them to be distressing (Wu, Rudy & Storch, 2014). Turner-Brown, Lam, Hotzclaw, Dichter & Bodfish, (2011) suggest that it is the stopping of these thoughts that may cause distress to the individual, not the actual experience of them. Repetitive behaviours in OCD tend to reduce the distress experienced from the intrusive thoughts (Wu, Rudy & Storch, 2014), whereas repetitive behaviour in ASD may serve a different purpose such as self-stimulatory behaviour (Cunningham & Schreibman, 2008). Studies suggest, there is less of an association between the repetitive behaviour and an anxiety provoking thought/obsession in individuals with ASD (Mack et al., 2010), although when individuals with ASD are stressed, they may increase the frequency of their repetitive behaviours (Groden et al., 2005). Arguably the overlap of OCD and ASD symptoms may increase the challenge of differentiating between the two disorders (Wu et al., 2014) and this may impact on determining the appropriate treatment and intervention of individuals with ASD.

1.5 PSYCHOLOGICAL TRIGGERS OF ANXIETY

This section focuses on the ways in which the core features of ASD may increase the likelihood of the individual with ASD experiencing increased anxiety.

1.5.1 Social and communication impairments and anxiety

As discussed, there is likely to be a bi-directional relationship between the social anxiety experienced by an individual with ASD and their social and communication impairments (White et al., 2010). Furthermore an individual with a deficient theory of mind such as individuals with ASD may experience, may further contribute and increase the risk of social anxiety (Baron-Cohen, 2008). Theory of mind refers to an individual's ability to understand and perceive others' points of view and be able to interpret the meaning of their behaviour and behavioural intentions (Baron-Cohen, 1995). It may be that having an awareness of one's difficulty in understanding other's thoughts, feelings and intentions increases the likelihood of social anxiety (Mazefsky & Herrington, 2014). For those individuals with ASD who are socially motivated and desire to form friendships, the difficulty in understanding and interpreting others' intentions in a social situation is likely to further increase their anxiety (Mazefsky & Herrington, 2014).

Research suggests that behavioural problems such as tantrums and repetitive and stereo-typed behaviours may increase as a result of an individual with ASD fearing rejection and negative evaluation in social contexts (Wood & Gadow, 2010). The individuals' level of functioning will impact on the extent to which they may experience anxiety in social settings, some individuals with ASD being more aware of others' reactions, and as a result of their social and communication impairments may misinterpret others' intentions. Subsequently,

the individual learns to expect a negative outcome in social interactions which may develop into a broader fear of being negatively evaluated by others (Mazefsky & Herrington, 2014). A fear of being negatively evaluated by others is core feature of social anxiety (APA, 2013).

1.5.2 Repetitive behaviours and anxiety

Research suggests that anxiety may lead to an increase in repetitive behaviours that may be used as a coping mechanism to manage the anxiety (Mazefsky et al., 2013). The relationship between repetitive behaviours and anxiety is likely to be bi-directional, with the presence of anxiety increasing the frequency of repetitive behaviours that in turn may increase the likelihood of anxiety. Interestingly, Guttman-Steinmetz, Gadow, DeVincent & Cromwell (2010) reported that there was a stronger association between symptoms of anxiety and obsessive and repetitive behaviours in ASD, than between social and communication impairments in ASD and anxiety.

1.5.3 Resistance to change

A common issue reported in autism is the difficulty that autistic children may experience adjusting to change and transition (Mazefsky & Herrington, 2014). Research exploring an association between resistance to change and anxiety is limited. A study by Mazefsky, Conner & Oswald (2010) found that one third of their sample of high functioning adolescents with ASD satisfied the criteria necessary for clinically significant transition related anxiety. Rodgers, Glod, Connolly & McConachie (2012) in his study comparing adolescents with ASD with and without anxiety, found that in the sample with anxiety, resistance to change was associated with anxiety. In the group with low anxiety, resistance to change was not found to be associated with anxiety. This was reflective of findings in neuro-typical populations, in which intolerance of uncertainty can

differentiate between those who are and are not considered to be clinically

anxious (Dugas, Gagnon, Ladouceur & Freestone, 1998).

1.5.4 Differences in sensory processing

Sensory dysfunction is also thought to relate to the level of anxiety a child with

ASD might experience. For example, an autistic child who is hypersensitive and

therefore has a low threshold for processing sensory information is likely to

become increasingly anxious in situations in which they are unable to control the

amount of stimulation that they are experiencing (Mazefsky & Herrington, 2014).

Studies researching a link between hypersensitivity and anxiety has been found

to be inconsistent, perhaps due to methodological errors (Kerns & Kendall,

2012) or perhaps due to the complex nature of the relationship and other

underlying variables which may impact on the levels of anxiety experienced. For

example, Dinstein et al., (2012) found that sensory information could be

perceived differently, at different times by the same individual producing a

different neurobiological response across time. These authors suggest that

unpredictable responses to sensory stimuli could be anxiety provoking for

autistic individuals given their desire for sameness and consistency.

1.5.5 Transdiagnostic behavioural processes

In order to further our understanding of the contributing variables to anxiety, it is

useful to explore transdiagnostic processes, which focus on examining and

exploring the etiologic mechanisms present across disorders. This helps to

inform our knowledge of anxiety together with comorbidity across disorders

(Nolen-Hoeksema and Watkins, 2011) in this case ASD and anxiety.

1.5.5.1 Obsession/rumination and anxiety

The term "perseveration" in ASD is used to describe the obsessional way in which autistic individuals may become stuck on things that they are interested in and enjoy. Autistic individuals are often known to have specific interests that they enjoy. In addition to enjoying particular interests, autistic individuals may also become preoccupied with unpleasant or distressing ideas and may find it hard to shift their thoughts away from these ideas. This may lead to anxiety or other emotional concerns (Mazefsky, Pelphrey & Dhal, 2012). It has been suggested that perseveration is similar to the way in which anxious individuals in a typically developing population may "ruminate" defined as being "the tendency to think persistently about emotional topics" (Mazefsky & Herrington, 2014, p.94). Evidence suggests that rumination is a core component of anxiety and depression (Siegle, 2008).

1.5.5.2 Emotion regulation

Emotion regulation can be described as being the way in which an individual is able to control his/her emotional reactions to promote a desired behaviour (Cole, Martin & Dennis, 2004). Research suggests that problems with the way in which an individual is able to manage their emotions play a central role in the development of anxiety disorders (Cisler, Olatunji, Feldner & Forsyth, 2010). Some studies suggest that it is the individual's desire to suppress emotions and the less effective use of coping strategies that may result in increased anxiety (eg Amstadter, 2008).

In their study on emotion regulation in Asperger's syndrome and high functioning autism, Samson, Huber, & Gross (2012) found that adults with ASD self reported a greater use of suppression and less cognitive appraisal techniques than typically developing adults. Core diagnostic features of ASD

may interfere with the way in which an autistic individual is able to regulate their emotions. Social impairments, the desire for sameness and routine, and sensory processing difficulties, may contribute to difficulties regulating one's emotions. For example, Mazefsky et al., (2013) suggest that the difficulty adjusting to change and the desire for rigidity may interfere with the way in which the individual is able to flexibly manage their emotions. Mazefsky et al., (2013) also suggest that social impairments in ASD may impact the way in which an individual is able to time their emotional response due to their difficulties in perceiving and understanding other's social cues and reactions. Furthermore, research suggests that individuals with ASD experience greater levels of distress and irritability in early childhood, which may lead to the development of maladaptive emotion regulation strategies later in life (Cisler et al., 2010).

Thus it seems that the core symptoms of ASD may increase the difficulty of regulating one's emotions and therefore increase the likelihood of experiencing anxiety. Given the extent to which individuals with ASD experience anxiety together with other emotional disorders it may be beneficial to consider whether the treatment of emotional regulation should become an essential part of interventions with individuals with anxiety and ASD (Mazefsky et al., 2013).

1.6 IMPACT ON PARENTAL MENTAL HEALTH AND FAMILY LIFE
1.6.1 Parental mental health of children and adolescents with ASD
Parents of children with ASD experience significantly higher parenting stress (Rao & Beidel, 2009; Hayes & Watson, 2013) and more depression and anxiety symptoms (Baker, Seltzer, & Greenberg, 2011; Benson & Karlof, 2009) than parents of typically developing children or children with developmental disabilities such as Down syndrome. In comparison to mothers of children with Down syndrome or mothers of neuro-typical children research suggests that

mothers of autistic children report less perceived parenting competence, less marital satisfaction, and higher levels of depression. Compared with other childhood disorders, Benson (2006) notes that the impact of autism on the family appears to be particularly severe, with parents of children with autism reporting high levels of stress associated with their child's social, communicative and behavioural problems.

Studies suggest that parents experience the most stress when their children exhibit problematic behaviour (Benson, 2006; Hastings, 2003). Gray (2002) in his longitudinal study of families of children with autism found that in families in which children with ASD did not experience severe behavioural difficulties, parent's stress levels improved as the children matured. Research suggests that the impact of anxiety on children with ASD can be that the child is likely to exhibit more behavioural problems and it is often these behavioural problems that parents find most difficult to deal with (eg. Estes et al., 2009; Quine & Pahl, 1985; Weiss, 1991)

The stress on parents of children with ASD may increase as the child becomes an adolescent. Studies have indicated that adolescents with ASD are at greater risk for developing anxiety owing to them becoming increasingly aware of their social deficits (White et al., 2010). The relationship between anxiety and social deficits in ASD may be cyclical in nature, with heightened awareness of their limitations in social skills contributing to increased anxiety that may in turn exacerbate the adolescent's social problems (White et al., 2010). Unlike typically developing adolescents, adolescents with ASD may continue to be dependent on their parents, thus their parents do not experience the lessening of responsibilities which parents of typically developing adolescents might (Reaven et al., 2009).

Longitudinal research on the family well-being and behavioural problems suggests the presence of a bidirectional relationship between childhood behaviour problems and parental wellbeing (Hastings 2003). Some recent studies have focused on the emotional well-being of mothers of adolescents and adults with ASD. This research suggests that maternal stress may persist over time. For example, Peters-Scheffer et al., (2011) suggest that maternal stress and child behavioural problems remained stable over time with the autistic child's emotionally reactive and withdrawn behaviour, and attention problems being predictive of maternal stress. Similarly, Lecavalier, Leone & Wiltz (2006) suggest that behavioural problems significantly contribute to parental stress and that this is bidirectional in nature.

Much of the literature on parental stress in families with autism has been predominantly based on mothers' experiences. This may be as a result of fathers being more difficult to access in research. Vacca (2013) reported that fathers identified reasons for not participating in research as being due to their job and family obligations, or personal feelings. Research suggests that when fathers are involved with their children with disabilities and included in treatment programmes, they report higher levels of satisfaction in their marriage, higher perceptions of themselves as a parent, and higher self esteem and confidence (Vacca, 2013).

Fisman, Wolf & Noh (1989) reported that fathers of children with ASD experienced more stress and less intimacy in their marriage compared with fathers of Down syndrome or typically developing children. In their qualitative study of fathering a child with ASD, Martins, Walker and Fouche (2013) suggested that fathers of children with ASD experienced stress related to their child's behaviour and this impacted on their own well-being. These fathers felt

that their wives experienced greater contact with their child than themselves, perceived that there was more conflict within their marriage and felt socially isolated as a result of their child's challenging behaviour. However, further research needs to be carried out to include fathers to be able to understand fully the needs of the family with autism and the how the interplay of relationships and dynamics within the family interrelate. This is especially important in furthering our understanding of the family's needs in terms of intervention and treatment (Seligman & Darling, 2007).

1.6.2 Parental perspectives on the nature of anxiety and ASD

In one of the few studies on parental perspectives on the nature of anxiety in children with ASD, Ozsivadjian et al., (2012) used focus groups in which seventeen mothers of nineteen children with ASD (aging from 7-18years) participated. Parents reported that the impact of anxiety was often more substantial than the impact of ASD itself. Parents reported that their children had difficulty expressing their worries verbally and most showed their anxiety through changes in their behaviour. Behaviour was described as being the means in which children with ASD were able to demonstrate their anxiety. Children with ASD were said to be highly dependent on their parents when managing their anxiety and this impacted on how the family was able to function. It was felt that as a result of the anxiety, quality of life was further diminished and that the anxiety had a greater part to play in this than the ASD itself. Parents expressed feelings of guilt and frustration in not being able to help their children effectively manage their anxiety.

1.6.3 Parental self-efficacy

Parental self-efficacy (PSE) has been described as being the parent's belief in their ability to be a successful parent (Jones & Prinz, 2005) and it has been

linked with the use of positive parenting strategies, and coping in demanding situations for parents (Jones & Prinz, 2005). Positive self efficacy has also been associated with less psychological distress (Coleman & Karraker, 1998; Hassal, Roser, & McDonald, 2005) and has been associated with parental stress and depression in parents of children with ASD (Kuhn & Carter, 2006; Meirsschaut et al., 2010). PSE has been found to mediate the effect of child behaviour problems on mother's anxiety and depression and moderate the effect of child behaviour problems on paternal anxiety (Hastings & Brown, 2002). In Giallo et al.'s study (2013) fatigue and exhaustion were found to have a negative impact on PSE, with mothers who reported high levels of fatigue feeling less efficacious and less satisfied in their parenting role. Thus, it is important to recognize that low parental self-efficacy beliefs have been shown to be related to stress and depression in parents of children with ASD.

1.6.4 Impact on families

Evidence suggests that families with an autistic child are at greater risk for experiencing psychological difficulties compared to other disabilities because of the social difficulties and impairments associated with autism (eg Dunn, Burbine, Bowers, & Tantleff- Dunn, 2001). The social, behavioural and communication impairments can impact the way in which family members are able to relate to the autistic child (Meadan, Stoner & Angell, 2010) and may effect the way in which the family is able to adapt to having a child with autism (eg Morgan, 1988). In comparing families with autism to families with other disabilities, Bebko, Konstantareas & Springer (1987) found that these families experienced greater disruption to family life, and were able to participate in fewer leisure type activities as a result of their autistic child's impairments. The severity of the condition (Abbededuto et al., 2004), the child's age (Smith, Seltzer, Tager- Flusberg, Greenberg, & Carter, 2008) and gender (Mandell & Salzer, 2007)

have also been found to impact on the psychological well-being and coping approaches of parents of children with ASD.

Families with an autistic child have also been found to experience more difficulty adapting to the disability as a result of the behavioural problems that can be a core impairment in autism. Bailey (2007) noted that in families where a child exhibits challenging and difficult behaviour, families have found it harder to adapt. Further research suggests that problematic behaviours in children with autism can have a negative effect on the well-being of parents and sibling relationships (Morgan, 1988; Seltzer et al., 1997).

1.6.5 Sibling relationships

Research regarding the quality of the autistic child's relationship with their sibling is mixed. Kaminsky and Dewey (2001) found that relationships between a child with ASD and their typically developing sibling may be less intimate, and less nurturing than a relationship with a child with Down syndrome or a neuro-typical sibling. Similarly, Knott, Lewis & Williams (1995) reported that siblings that included an autistic child were said to spend less time together, and to initiate with one another less than those siblings that included a child with Downs syndrome or a typically developing child.

In contrast some research suggests that siblings that include an autistic child rate their relationship with their sibling more positively than those with a neuro-typical child. For example, McHale, Sloan, & Simeonsson (1986) found that siblings including a child with Downs syndrome or ASD reported there to be less conflict and competition within their relationship than typical sibling pairs. Roeyers and Mycke (1995) reported that those siblings that included a child with

a disability spoke more highly of their sibling relationship than typical sibling

pairs.

1.7 AUTISM AND ANXIETY IN SCHOOL

1.7.1 Research on autism and anxiety in school

Research on anxiety in children and adolescents with ASD in schools has been

limited, yet evidence suggests that a high percentage of adolescents with ASD

experience anxiety-related problems (White et al., 2009; Szatmari & McConnell,

2011). Youth spend a large proportionate amount of time in school settings, and

research suggests that anxiety may contribute to decline in academic

performance, interpersonal relationships and increased behavioural problems in

students with ASD (Kim et al., 2000; Reaven, 2009). The school setting can be

a stressful environment for adolescents with ASD, placing social,

communication and sensory demands on them which they may find challenging

to cope with. The environmental demands together with the adolescents'

difficulties adapting is likely to contribute to anxiety and stress (Lopata &

Thomeer, 2014). Morgan (2006) highlights that chronic exposure to high levels

of anxiety can lead to long term negative effect on memory, learning and brain

functioning, thus highlighting the need to understand contributory factors to

anxiety within school settings and appropriate interventions for adolescents with

ASD.

Studies suggest that adolescents with ASD had significant problems coping with

the academic needs, with perfectionism and the demands of the classroom

(Ashburner, Zivizni & Rodger, 2010). Lecavalier (2006) examined the

prevalence of anxiety and other emotional and behavioural problems in

adolescents with ASD. Teacher ratings reported 11-18% of the sample to have

moderate or severe problems feeling nervous, tense, fearful or anxious. Gjevik

et al., (2011) found that 72% of students with ASD in a special school met the criteria for at least one comorbid disorder, with anxiety disorders being the most common at 42%. The authors suggested that these findings may have been high due to the sample being taken from a special school as opposed to a population-based sample of students with ASD.

1.7.2 Contributing factors to anxiety within schools

Contributing factors to anxiety within school settings include the difficulties individuals with ASD may have understanding social communication and reciprocation and the efforts needed to engage in social exchanges may result in feelings of distress and anxiety (APA, 2013; Portway & Johnson, 2005). As mentioned earlier cognitive ability and age may affect the extent to which an individual with ASD experiences anxiety. Higher functioning, older students may be more likely to experience anxiety although Lopata and Thomeer (2014) suggest that it may be that younger and lower functioning students are less able to communicate feelings of anxiety due to their communication impairments. Research also suggests, that bullying may be a contributory factor to anxiety within schools, leading to loneliness and isolation (Church, Alisanski & Amanullah, 2000). Unfamiliarity with others may also cause anxiety and stress in higher functioning individuals with ASD (Lopata, Volker, Putnam, Thomeer & Nida, 2008). Individuals with ASD often desire structure and routine and may have difficulty adjusting to change. The school environment is often susceptible to change, and unanticipated changes to routine may result in increased anxiety (Morgan, 2006). The transition to secondary school together with the changes incumbent at the beginning of the year may be a particularly anxiety provoking and stressful time for students with ASD (Ashburner et al., 2010). Exposure to certain sensory stimuli may also be distressing for some adolescents with ASD

and research suggests that schools should be aware of individual's sensory needs (Ashburner et al., 2010).

1.8: PSYCHOLOGICAL INTERVENTION FOR ANXIETY IN CHILDREN WITH ASD

1.8.1 Empirically supported treatment for anxiety disorders in youth

Cognitive behavioural therapy is seen as being one of the most effective approaches in treating anxiety (eg Davis, May & Whiting, 2011, Kendall et al., 1997). CBT programmes include common elements such as psychoeducation, exposure, cognitive restructuring, parent training, or parent psychoeducation, relaxation, modeling, and self-monitoring (Rotheram-Borus et al., 2012). Furthermore, interventions designed specifically for individuals are likely to be more efficacious than manual treatments (Weisz et al., 2012).

1.8.2 Treatment of anxiety for individuals with autism

CBT has been recognized as an empirically supported intervention for children with anxiety (Davis, 2009; Davis & Ollendick, 2005). Recent literature has begun to examine the use of CBT as a treatment intervention for children who present with anxiety and ASD. Studies examining the effectiveness of CBT for children with anxiety and ASD have shown promising results with participants showing reductions in symptoms of anxiety (Chalfant, Rapee & Carroll, 2007; Reaven et al., 2009, Sofronoff, Atwood, & Hinton, 2005). Moree and Davis (2010) suggest that with certain modifications CBT can be used to treat anxiety in children with ASD, with the need to consider the child's cognitive ability. These authors suggested modifications such as the importance of tailoring the programme to meet the child's needs, the inclusion of the child's special interests to develop rapport and the use of specific and visual strategies to explain new concepts. They also recognized the importance of engaging with parents and including

them in the treatment plan. Danial and Wood (2013) suggest that the child's special interests can be incorporated into the programme as a reward and to increase motivation.

Dongoghue, Stallard & Kucia (2011) also published an approach to CBT for children with ASD suggesting the need to develop a collaborative partnership recognizing the child's unique strengths and difficulties; ensuring the intervention is pitched at the appropriate developmental level for that child; the use of visual cues; the inclusion of parents and the need for empathy and creativity in tailoring the programme to meet the child's individual needs. Although the intervention itself may not look disimiliar to a CBT approach used for a neuro-typical child with anxiety, the delivery of the intervention may be different for an autistic child (Sofronoff, Beaumont & Weiss, 2014).

In Lang, Regester, Lauderdale, Ashbaugh & Haring's (2010) review of CBT treatments in children with Asperger's or high functioning autism, the authors outlined the recommended types of modifications. These included the use of increased social interaction skills and increased use of visual aids. As above, the child's special interest was also incorporated into the programme to increase motivation and understanding of the concepts, together with inclusion of parents to further reinforce desired behaviours. Scattone and Mong (2013) suggest that a modified CBT programme for children and adolescents with ASD may include more social skills and a focus on emotion regulation, greater parental involvement, increased use of visual aids and tailoring the pace of the CBT to the needs of the individual. Other studies support these findings suggesting that CBT may be an efficacious intervention for anxiety in children with ASD, demonstrating significant reductions in the reporting of anxiety symptoms (eg

Reaven, Blakeley- Smith, Culhane- Shelburne & Hepburn, 2012; Keehn,

Lincoln, Brown & Chavira, 2013).

The need for effective school interventions to reduce anxiety in students with

ASD is clearly needed, as anxiety can negatively affect long term outcomes

(APA, 2013). Despite this need, there is a lack of school based interventions

targeting anxiety in students with ASD. Reaven (2009) posits that a multimodal

approach to treating anxiety is needed for students with ASD and this requires a

multidisciplinary team. Research suggests that CBT may be most appropriate

for high functioning individuals with ASD due to the need for cognitive and

language abilities. For those students with lower functioning abilities, it seems

that behavioural techniques may be more appropriate (Bolton, McPoyle-

Callahan, & Christner, 2012; Chang, Quan & Wood, 2012). Although

researchers have developed different treatment packages, the interventions

share common elements (eg Reaven et al., 2012; White et al., 2013). The

programs include psychoeducation, cognitive restructuring, problem solving and

the use of techniques such as controlled breathing and progressive muscle

relaxation are encouraged (Groden, Baron & Groden, 2006). Exposure

techniques can be used within schools providing students the opportunity to

practice coping and relaxation strategies (Lopata & Thomeer, 2014). Anxiety

treatments that have included a social skills element have shown positive

results. Social skills training has been included to help individuals with ASD

improve their social communication, with the aim of then reducing their anxiety

in social situations. This training can be done through role-play, rehearsal and

feedback (Bolton et al., 2012).

Lickel, MacLean, Blakeley-Smith & Hepburn (2012) explored what prerequisite

skills may be necessary in order for CBT to be successful for children with ASD.

They questioned whether cognitive skills, such as the ability to recognise emotions, to be self-reflective and to take other's perspectives, required to participate in CBT may be particularly difficult for children with ASD. Their results suggested that the children with ASD produced comparable results to typically developing children on all tasks except on their ability to recognise emotion. They suggest that the CBT programs should include components to teach and help children with ASD understand about their emotions. This is supported by research that suggests that children with ASD are able to learn how to increase their understanding and awareness of emotions (Golan et al., 2010).

Ozsivadjian and Knott (2011) note that it may be difficult for children with ASD to engage with CBT because of their difficulties in communication and social understanding. Another limitation highlighted by Reaven et al., (2015) is that although the studies have demonstrated a reduction in symptoms of anxiety there is still a percentage of children who demonstrate little to modest reduction in anxiety following treatment. These authors suggest that it is important to understand other factors such as parental anxiety that may influence the treatment response. Whittingham, Sofronoff, Sheffield & Sanders (2009) suggest that given the behavioural problems that a child with ASD is likely to experience, it may be beneficial for parents to attend a parenting program before commencing an intervention for the child.

Sofronoff et al., (2014) suggest that a transdiagnostic approach may be useful in treating anxiety in children with ASD. Evidence suggests that youth with ASD experience a range of emotional problems resulting in both internalizing and externalizing symptoms. Emotions such as sadness, anger, anxiety are common amongst those who experience anxiety and in adolescents with ASD. A core

component of transdiagnostic models is that of emotion regulation (McLaughlin, Hatzenbuehler, Mennin & Nolen-Hoeksema et al., 2011). Through furthering our understanding of the ways in which children and adolescents with ASD regulate their emotions and the challenges they face in doing so, Mazefsky et al., (2013) suggest that this will further the development of effective interventions for this population.

1.8.3 Parental anxiety and treatment response

There has been little research exploring the relationship between parental anxiety and treatment response in children and adolescents with ASD and anxiety but the results indicate that parental trait (chronic) anxiety significantly decreased from pre-to post treatment for parents of children who responded to treatment (Reaven et al., 2015). Conner, Maddox & White (2012) found that that parental state anxiety correlated with the severity of adolescent anxiety and that parents of adolescents who responded to treatment experienced a decrease in their own trait anxiety. These studies indicate that a parent's chronic anxiety reduces with the reduction of anxiety in their child and that the anxiety they experience is related to the severity of their child's anxiety. This implies that a parent's mental health may improve with an improvement in their child's mental health. This highlights the importance of understanding the association between parental and child anxiety and the impact this may have on treatment outcome.

1.8.4 Role of parental participation in treatment

Parental participation in the treatment of anxiety in children has been found to be positive (Barrett, Healy-Farrell, & March, 2004; Cobham, Dadds, & Spence, 1998; Reaven & Hepburn, 2006) with the greatest benefit of parental involvement being apparent for younger children (Barrett et al., 2004) although it is not known how long these gains are maintained over time. Children with ASD

especially benefit from parental involvement as parents are in a position to implement continuous treatment (Koegel, Bimbela & Schreibman, 1996), reinforce their child's learning outside of school and help the generalisation of their skills (Boton et al., 2012).

Research has indicated that parental stress may reduce the success of the outcomes of treatment with children with ASD (Greenberg, Seltzer, Hong & Orsmond, 2006; Rao & Beidel, 2009). Studies on the impact of parenting stress in early teaching interventions for children with ASD indicated that high levels of parenting stress counteracted the effectiveness of the early teaching interventions (Osbourne, McHugh, Saunders, & Reed, 2007) with fewer successes displayed when parents reported high feelings of stress. It is recommended to assess the mother's mental health prior to participating in treatment so that symptoms of depression and anxiety can be addressed (Kuhn & Carter, 2006; Rao & Beidel, 2009).

Evidence suggests that because of the particular challenges of children with ASD, parents are likely to play a larger role than those parents of normally developing children (Reaven et al., 2009). Studies using CBT to treat anxiety and ASD in children have highlighted the importance of parental participation (Chalfant et al., 2007; Sofronoff et al., 2005; Wood et al., 2009). Sofronoff et al., (2005) evaluated the effectiveness of a CBT intervention for anxiety with children with AS in which active parental involvement was found to enhance the usefulness of the programme, there being significant benefits for the parents themselves and the children.

The parental role in treatment with adolescents has been relatively unexplored (Reaven, 2011). Most of the studies using CBT to treat anxiety and ASD have

focused on children under the age of 13 years and there have only been two treatment studies which specifically targeted adolescents (White et al., 2009; Reaven et al., 2009). Reaven (2011) outlined several recommendations for parents when involving them in the treatment of their child with anxiety and ASD with particular emphasis for parents of adolescents. These include the importance of acknowledging and addressing family stress and providing parents with the opportunity to discuss their concerns in relation to their child or adolescent with ASD and anxiety. Reaven (2011) recommends increasing awareness of parenting factors such as parenting anxiety and parenting style and how these factors may result in protective parenting. She suggests encouraging the role of coach that can provide a positive experience for both parent and adolescent.

Studies have indicated that not only can parental involvement be beneficial for the child but can also be beneficial for the parent. By being given the opportunity to learn new skills that will improve their child's well being, parents experience increased positive affect (Koegel et al., 1996), reduced stress (Symon, 2001) and improved self-efficacy (Feldman & Werner, 2002). In addition, when parents are treated as partners with clinicians in programs in which they are able to help develop goals and treatment plans for their children, results have indicated a reduction in parenting stress, higher levels of confidence and more positive parent child interactions (Brookman-Frazee, 2004).

1.9 SUMMARY

Autism is described as being a complex, neurodevelopmental disorder characterised by core deficits in social interaction, communication and repetitive or stereotypic behaviour (APA, 2013). Individuals with ASD may have difficulty interacting with others and lack reciprocal social skills. They may experience

delays in language and have restricted interests, and have a desire for rigid routines (Wu, Rudy & Storch, 2014). Autism is more prevalent in males than females and is thought to have a genetic aetiology (Aarons & Gittens, 2002). Individuals with autism are likely to experience a range of comorbid disorders including learning impairments, behavioural and psychiatric disorders. There is high variability within autism, with factors such as developmental level, language delay, IQ, and possible comorbidity influencing the severity of symptoms an individual may experience (Lecavalier, 2014). Interventions should be intensive and introduced at an early age in order to produce optimal outcomes, together with the need to take into account the child's individual needs given the variability of autism spectrum disorder.

Evidence suggests that anxiety is one of the most common psychiatric disorders experienced by children and adolescents and that they are highly comorbid with other emotional disorders (eg. Cartwright-Hatton et al., 2006; Brady & Kendall, 1992). It has been suggested that anxiety disorders may result from environmental, temperamental and genetic/physiological factors and may be maintained by cognitive distortions resulting in the experience of physiological symptoms and avoidance behaviour (eg. Muris & Ollendick, 2005; Tiet et al., 2001; Eley & Gregory, 2004). CBT together with pharmacotherapy has been found to be the most effective treatment for anxiety disorders in childhood and with some evidence for optimal success when parents are included in the treatment programme (eg. March, 2009).

Anxiety has been seen to be entwined with ASD and as such it is only since the late 1990's that research into anxiety in ASD has increased (Kerns & Kendall, 2014). The issue of whether anxiety symptoms in ASD is best described as a core feature of ASD, as a comorbid disorder or as an alternative type of anxiety

within ASD continues to be debated (Kerns & Kendall, 2012; Wood & Gadow, 2010). The relationship between the two is likely to be bidirectional with the symptoms of autism resulting in an increase in anxiety, which in turn may exacerbate the symptoms of autism (White et al., 2010). Mason and Scior (2004) suggest that diagnostic overshadowing may contribute to the tendency for anxiety in ASD to be attributed to the more dominant disorder of ASD rather than being seen as an additional comorbid anxiety disorder.

Research suggests that children and adolescents with ASD are more likely to experience anxiety than neuro-typical children or children with learning difficulties (Gadow et al., 2005). Anxiety has been found to increase with age and level of functioning (eg Lecavalier, 2006; Kuusikko et al., 2008), and can have a serious impact on individuals with ASD (Greig & Mackay, 2005), effecting their academic performance, peer relationships and family life (Bellini, 2004; Sze & Wood, 2007). White et al., (2014) argue that anxiety needs to be assessed and accurately diagnosed in individuals with ASD so that the appropriate intervention for these individuals can be undertaken.

Core features of autism such as social communication impairments, repetitive behaviours, resistance to change, and sensory dysfunction may lead to increased anxiety in individuals with ASD (eg. Wood & Gadow, 2010; Mazefsky et al., 2013). Transdiagnostic models that explore etiologic models across different disorders suggest that difficulties in regulating one's emotions may be an underlying component in the development of anxiety disorders. Furthermore, research suggests that these core diagnostic features of autism may also interfere with the way in which autistic individuals are able to regulate their emotions, thus further increasing the likelihood of an anxiety disorder. Mazefsky

et al., (2013) highlights the need for emotion regulation to form a core part of intervention for individuals with autism.

There are several limitations in the research methodology to date. For example, studies have mostly used assessment measures developed for neuro-typical individuals with anxiety and therefore do not necessarily take into account the ways in which anxiety may be experienced differently by those with ASD (Kerns & Kendall, 2014). Studies have also used both informant and self-report measures both of which have their limitations. Informant measures may lead to inaccuracies as a result of the reliance on others to describe the individual's behaviour, and self report measures may be unreliable due the difficulties the individual may have in communicating and reporting their symptoms (Kerns & Kendall, 2014). As a result of this, the percentage of autistic individuals experiencing significant anxiety may have been underestimated in the literature.

The literature on parental stress and the impact of autism on families indicate that parents of children with ASD may experience higher levels of stress, fatigue, anxiety and depression than those of parents of typically developing children or of children with other types of developmental disabilities (eg. Baker et al., 2011). A child who suffers from anxiety and ASD may experience increased behavioural problems possibly causing further psychological distress for the parent (eg. Estes et al., 2009). The research suggests that the relationship between the parent and child's anxiety is bidirectional, and indicates that low parental self-efficacy is related to stress and depression in parents (Hastings 2003; Kuhn & Carter, 2006).

The literature on autism and anxiety in schools suggest that a high percentage of adolescents with ASD experience anxiety related problems at school (White

et al., 2009). Research has highlighted that chronic exposure to anxiety can have a negative impact on memory and learning in the long term, thus emphasising the need to develop appropriate interventions for autistic individuals in the school environment (Morgan, 2006). Contributing factors to anxiety at school for adolescents with autism include the need for social interaction and communication, bullying, difficulties adapting to change and transition within the school day.

Research on intervention for anxiety in children with ASD indicates that with certain modifications, CBT may be an appropriate intervention for higher functioning children, resulting in the reduction of anxiety symptoms (eg. Moree & Davis, 2010). Furthermore, it has been suggested that CBT should include components to help children with ASD to understand and increase awareness of their emotions (Lickel et al., 2012). Parental anxiety has been associated with child anxiety, and research suggests that parental mental health may improve with the reduction of their child's anxiety (Conner et al., 2012). The role of parental participation in treatment has shown promising results, studies suggesting that parental involvement helps to implement continuous treatment for the child, improve parent's confidence, and lead to more positive parent child interactions reducing parental stress (Brookman-Frazee, 2004).

1.10 RELEVANCE TO COUNSELLING PSYCHOLOGY

Counselling psychologists are entering into the field of children and adolescent mental health although this has not traditionally been an area in which they have worked. Given the increasing prevalence of children and adolescents being diagnosed with ASD and the high percentage of children with ASD who present with both typical and atypical symptoms of anxiety, counselling psychologists will work with this population on an increasingly frequent basis. Research

suggests that a modified and tailored CBT programme may be an effective intervention for anxiety in children with ASD (eg. Moree & Davis, 2010). The research has highlighted the importance of considering parental anxiety and the impact that this may have on the outcome of treatment for their child (eg. Greenberg et al., 2006). The role of the counselling psychologist is key in working with both the parent and child to help identify the triggers and manifestation of anxiety in the individual with ASD. In assessing and formulating the parent and child's needs, the counselling psychologist is able to work relationally to determine the most appropriate psychological interventions for the individual and their family.

1.11 CONCLUSION

In clinical settings anxiety related concerns are among the most common presenting problems for school age children and adolescents with ASD (Ghaziuddin, 2002). Research suggests that children with ASD experience more symptoms of anxiety than typically developing children or children with learning difficulties, language impairments, Down syndrome and Williams syndrome (Gadow et al., 2005). Whether anxiety symptoms are representative of a core feature of ASD or indicative of a comorbid anxiety disorder continues to be explored, with studies suggesting that the relationship between anxiety and ASD is bi-directional (Kerns & Kendall, 2012). Anxiety can detrimentally impact the individual's ability to perform well at school, to develop relationships with others, and impacts the way in which the family is able to function.

Research suggests that parents of children with ASD experience higher levels of stress and anxiety than parents of typically developing children or children with other developmental disabilities (eg Baker, Seltzer & Greenberg, 2011). One of the only studies on parental perspectives on anxiety in ASD (Ozsivadjian, Knott

& Magiati, 2012) suggest that it is the impact of anxiety which was more substantial than the impact of ASD itself. Parents felt that their child's anxiety impacted on family life, and diminished their quality of life more so than the ASD.

CBT with modifications, currently shows some promising results in treating anxiety in individuals with ASD. However, research suggests that there are still a percentage of children who demonstrate little improvement in anxiety symptoms following treatment (Reaven et al., 2015). Some authors suggest that difficulties regulating one's emotions underlies the anxiety which individuals with ASD experience, and that emotion regulation should form a core part of any intervention programme for children and adolescents with ASD (Sofronoff et al., 2014; Mazefsky et al., 2013).

Not all individuals with ASD experience high levels of anxiety with the trend being that anxiety increases with age and level of functioning ability (eg. Lecavalier, 2006; Kuusikko et al., 2008). Increasing our understanding of factors that contribute to anxiety in children with ASD will help to inform, guide and develop specific interventions for autistic children and adolescents who experience anxiety. This study aims to explore how mothers make sense of the experience of parenting a child with autism and anxiety in order to inform future interventions for children with autism and anxiety.

CHAPTER TWO: METHODOLOGY

2.1 INTRODUCTION

In this chapter I will outline the rationale for my study, provide a conceptual framework of Interpretative Phenomenological Analysis (IPA), the philosophical and epistemological underpinnings and my rationale for choosing IPA as opposed to other qualitative research methods. The second part of the chapter focuses on ways in which I have tried to ensure validity within my research, the method of data collection and the process of analysis.

2.1.1 Use of first person

I have used first person within this section to align myself with the phenomenological approach which emphasizes the role of the researcher and the process of reflexivity throughout my study (Smith, Flowers & Larkin, 2009).

2.2 CONCEPTUAL FRAMEWORK

2.2.2 Overview of Interpretative phenomenological analysis (IPA)

Interpretative phenomenological analysis (IPA) was used to explore how mothers make sense of their experience of parenting their child with autism and anxiety. Using IPA, semi-structured interviews were carried out with seven mothers of children aged between 10-16 years with ASD.

Qualitative research is concerned with understanding how people experience events and how they make sense of the world (Willig, 2013). Qualitative researchers are concerned with the meanings attributed to the events by the participants. The aim of IPA is to explore in detail how participants make sense of their personal and social world and what particular experiences mean for them (Smith & Osborn, 2008). The essence of IPA is its commitment to

understanding a person's experience and the ways in which they make sense of this experience (Smith et al., 2009). IPA would usually be used when the focus of a study is on understanding the significance that this lived experience has for somebody. In this study, IPA was used to focus on understanding the significance of the mothers' subjective experience of living with their child's anxiety. An interpretative phenomenological approach will enable the researcher to not only describe the participant's experiences but to generate knowledge about its meaning. This is particularly relevant for this study as through increasing our understanding of what these experiences might mean for mothers may help to inform the future development of interventions for anxiety in children with autism.

IPA mostly uses semi-structured interviews to collect data, which is then transcribed and analysed using a qualitative analytical approach. The researcher's interpretation is tentative, and suggestive of the possible underlying meaning of the participants account.

Smith et al., (2009) describe IPA as "an approach to qualitative, experiential and psychological research which has been informed by concepts and debates from three key areas of philosophy of knowledge: phenomenology, hermeneutics and idiography" (p.11). IPA draws on each of these theoretical approaches to inform its epistemological framework.

2.3 EPISTEMOLOGICAL FRAMEWORK

2.3.1 Phenomenology

Phenomenology is a philosophy initiated by Husserl (1927) that involved the thorough and attentive examination of human experience. He was particularly interested in finding a way in which an individual could begin to understand their

own experience of a given phenomenon and would subsequently be able to identify the essential qualities of that experience (Smith et al., 2009). IPA takes a phenomenological approach in which it is concerned with the detailed examination of human lived experience and thus focuses on the subjective experience of the individual as expressed by that individual. The participant is seen as the expert on her subjective experience, and analysis is concerned with the participant's perceptions of their experience, rather than what might be considered to be the reality (Jarrett, Payne, Turner, & Hillier, 1999).

Husserl proposed that underpinning the phenomenological approach is a key strategy of "phenomenological reduction" (Dowling, 2005 p.132). By this, Husserl referred to the way in which the researcher attempts to explore the phenomenon in as "free and unprejudiced" way as possible so that it can be described and understood in as unprejudiced manner as possible (Dowling, 2005 p.132). This method was intended to help the researcher to move away from his own assumptions about the phenomenology and towards an understanding of the essence of the experience (Smith et al., 2009). This is known as "bracketing", and is seen as a fundamental part of IPA in which the researcher is encouraged to be reflexive and reflect upon their assumptions throughout the research process.

2.3.2 Hermeneutics

Hermeneutics is the theory of interpretation and following Heidegger (1962/1927), IPA is concerned with examining how a phenomenon appears and what meanings can be attributed to the participant's account (Willig, 2013). Heidegger differed from Husserl in his view regarding the importance of interpretation within a phenomenological framework as opposed to the focus being solely descriptive (Dowling, 2005). Heidegger posits that through

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interpretation the lived experience can be understood (Racher & Robinson, 2003).

Heidegger (1962/1927) leads us to re-evaluate our use of bracketing, and the extent to which we can truly bracket our assumptions within our reflexive practice. Heidegger suggests that through our preconceptions and assumptions defined as being "fore-conception", we explore the phenomenon in a new light. Thus, the process of bracketing can be seen as a cyclical process in which our understanding is influenced by our fore-conceptions, which influence our understanding (Smith et al., 2009). Willig (2013) suggests that instead of bracketing our assumptions and fore- understandings as in descriptive phenomenology, the IPA researcher uses these assumptions and prior experiences to increase their understanding and knowledge.

Smith (2004) discusses the idea of the hermeneutic circle in which the process of interpretation is both dynamic and iterative. The hermeneutic circle refers to the notion that you can only understand the parts by understanding the whole, yet at the same time you cannot understand the whole without understanding the parts. The role of the researcher is very much engaged with and key in this process. Smith (2004) suggests that the researcher will not always be aware of their preconceptions and assumptions prior to the research and that these may change and evolve during the process of interpretation.

The role of the researcher in IPA is implicit in interpreting the data. IPA believes that participant's accounts are reflective of their attempt to make sense of a given experience and that the researcher needs to interpret the account to be able to understand the experience. Smith (2004) refers to "double hermeneutics" in which the researcher is trying to make sense of the participant trying to make

sense of their experiences (Shinebourne, 2011). Through the process of
reflexivity, the researcher needs to critically evaluate how their own experiences
and understandings may influence the research (Finlay, 2008).

Ricoeur (1970) distinguishes between two interpretative positions, a
hermeneutics of empathy and a hermeneutics of suspicion. Smith (2004)
suggests that within IPA different levels of interpretation are possible. He posits
that most of the interpretative levels are more aligned with the hermeneutics of
empathy and what the participant's experience means for them, but that IPA
allows for the hermeneutics of suspicion in that it enables the researcher to
question and suggest interpretations which the participant may have not been
able or willing to do. This process of suspicious interpretation uses critical
questioning to make sense of the participant's account and ascribe meaning to it
(Shinebourne, 2011). Smith et al., (2009) emphasise the need for hermeneutics
of suspicion in IPA to be grounded in the text. These reflections would be of a
speculative nature. Within the analysis, Smith (2004) suggests that the empathic
interpretation is likely to come first and is then followed by a more critical and
questioning speculative interpretation.

2.3.3 Idiography

Idiography is concerned with the particular in the sense of the detail and depth
of analysis required. IPA's emphasis is on the examination of a case in detail in
order to provide rich detailed data on a participant's account. It is thus said to be
idiographic in its approach and aims to explore the individual's experience, as
well as then going on to explore similarities and differences between participants
(Smith et al., 2009). This is in contrast to other methods that are nomothetic and
concerned with making claims at the group or population level. IPA aims to
understand how a particular experience has been understood from the

perspective of a particular population of people in a particular context (Willig, 2013). It therefore uses small, purposively select samples. In this study, seven mothers of children aged 10-16 years with a diagnosis of ASD were interviewed.

2.4 EPISTEMOLOGICAL STANDPOINT

Underpinning IPA is the phenomenological approach that focuses on providing knowledge about the subjective experience of the individual (Smith et al., 2009). A phenomenological approach posits that the same event can be experienced in many different ways (Willig, 2013) and that the way in which it is experienced is "real" to that individual. IPA subscribes to a relativist ontology believing that there are multiple ways in which a participant might experience the phenomenon and it aims to understand the meaning of the participant's subjective experience (Willig, 2013).

IPA also aligns itself with symbolic interactionism, meaning that an individual's understanding and interpretations are influenced by the ways in which they interact with their social environment (Willig, 2013). IPA pays particular attention to the relationship between the researcher and the participant and the researcher needs to be aware of how their relationship with the participant may affect the outcome of their research. The process of interpretation will be influenced by the assumptions and expectations of the researcher, the relationship between the researcher and the participant and the ways in which the participant experiences the phenomenon in question (Finlay, 2008; Larkin, Watts & Clifton, 2006). IPA requires the researcher to be reflexive recognizing that the researcher's interpretation of the data will be influenced by their understanding and assumptions (Willig, 2013).

My epistemological standpoint aligns itself with that of IPA and the way in which I work as a counselling psychologist. As a counselling psychologist, I am keen to explore the subjective experience of the client, my focus being to explore their understanding of their reality. I work integratively, and believe that there are multiple interpretations and multiple different ways of working with people at different moments in time.

The process of reflexivity and the role that the researcher plays forms an essential part of IPA. Throughout the research I have tried to become more aware of the assumptions that I may have been making and the ways in which these may influence my relationship with both the participant and the data. I have tried to increase my awareness of my assumptions through taking notes after the interview of my initial thoughts and reactions to the participant, through discussions with my supervisor and through noting my thoughts down in the form of a journal. This has helped me to continuously question the role in which I play as researcher, and increase my awareness of any influence I may have over the findings.

As a counselling psychologist I pay particular attention to the client-therapist relationship in my work, and in a similar fashion, I paid close attention to the relationship between myself and the participant during the interview. I was aware of not wanting to slide into the role of "therapist" and relied on my interview schedule to remind me to focus on the questions that I wanted to ask with the aim of furthering my understanding of the mothers' experiences. At the same time, I used the skills that I have developed through working as a counselling psychologist to develop rapport with the participant and put them at ease during the interview. I was aware that the participants may have found the

interview to be a therapeutic and emotional experience and at the end of the interview provided direction for further support if needed.

2.5 EPISTEMOLOGICAL REFLEXIVITY

One of the reasons for choosing IPA was that it seemed the most appropriate methodology to address my research question and that its epistemology seemed closely aligned with my own epistemological standpoint and the way in which I work as a counselling psychologist. In understanding the participant's subjective experience, and being aware of the multiple perspectives, it seemed to me that I would produce data which would help to understand how these mothers experienced their autistic child's anxiety. As the research progressed, I grappled with the question of whether I should instead have been exploring the underlying causes of the child's anxiety. I was aware, that to do this I would have needed to use an alternative research methodology. I began to feel frustrated that perhaps in exploring the mothers' experience, this may produce an analysis of limited value in helping to inform and guide the treatment of anxiety in autism. I reflected on my choice of methodology and read numerous IPA studies to increase my own understanding of the ways in which IPA is seen to be a valuable research tool. It became clearer to me over time that using IPA would enable me to gain an insider's perspective into the phenomenon of anxiety in autistic children and this understanding would be invaluable in helping to increase our knowledge of the relationship between anxiety and autism. By improving our comprehension of how mothers experience anxiety in their autistic children we will be in a stronger position to develop increasingly effective ways in which to help manage anxiety in this population of individuals.

I remained aware of the importance of the researcher-participant relationship in the research and how this might impact what the participant felt comfortable

discussing in the interview. This was of particular relevance to me as I had

recruited participants through word of mouth. This meant that although I did not

know my participants prior to the research, there were individuals that we

potentially both knew. I wondered in what way this may have changed the

interview, and wondered whether participants were more comfortable talking to

me because there was a commonality. I was also very conscious of ethical

considerations, in particular confidentiality, and took great lengths to ensure

anonymity for the participants.

2.6 PERSONAL REFLEXIVITY

I became motivated to study mothers' experiences of anxiety in families with

ASD when hearing from a friend about the difficulties her son with Asperger's

Syndrome experienced in the transition to secondary school. I searched for

articles on children who suffer from anxiety and ASD and became interested in

understanding more about the impact of anxiety for children with ASD and their

families.

Through my work with parents and children with ASD I have developed an

understanding of the anxiety experienced by children with ASD and how it can

impact on their behaviour at home and at school. I need to be aware of my

assumptions that anxiety may be the underlying cause of children's behavioural

problems and be open to other emotions that children with ASD may be

experiencing such as anger, frustration, sadness.

As a mother, I felt great empathy towards these mothers and needed to be

aware of my own experience of motherhood and any assumptions that I might

be making about their experience of motherhood. I found this challenging, and

tried to overcome it by ensuring that I asked open-ended questions throughout the interview and did not ask leading questions based on my own experiences.

I am aware that I have made some assumptions about anxiety in children with ASD and that at the beginning of the research I believed the anxiety to be a separate entity to the ASD for some children. This was as a result of my conversation with a mother of a child with ASD who said that the anxiety their child was currently experiencing was different to earlier experiences of anxiety that she believed had been part of the ASD. My reading also suggests that not all children with ASD develop significant symptoms of anxiety. In this study I was aware of this and tried not to ask leading questions about the child's anxiety that could support these assumptions. The question of whether the anxiety is part of the autism is one that I have pondered throughout my research, and how a mother and child can learn to manage the child's anxiety given the nature of the autism.

Throughout my research I have constantly challenged myself to be reflexive on both an epistemological and personal level. This has been demanding, and throughout the process I became increasingly aware of the need to be conscious of my own beliefs and possible impact on the research, my relationship with the participant, and how my beliefs and experiences could impact on the analysis. This will be discussed further in the discussion.

2.7 RATIONALE FOR USING IPA AS OPPOSED TO ALTERNATIVE APPROACHES

2.7.1 Interpretative versus descriptive phenomenology

I chose to employ the interpretative phenomenological approach as opposed to the descriptive phenomenological approach. Descriptive phenomenology is

concerned with describing the essence of the quality of the experience from the participant (Willig, 2013). Interpretative phenomenology seeks to understand the meaning of the experience and reflects on the meaning within a social and cultural context. My interest lies in exploring and gaining understanding of mothers' experiences of their child's anxiety and what meaning they may take from these experiences.

2.7.2 Grounded theory

Grounded theory (Glaser & Strauss, 1967) is seen as one of the main alternative approaches when considering IPA. Grounded theory aims to generate a theory or a framework to understand and account for the phenomenon being researched, thus enabling new theories to emerge (McLeod, 2011; Willig, 2013). This explanatory account is based on the views of a large number of participants and enables researchers to generate knowledge about theories of behaviour at a conceptual level (Creswell, 2007).

IPA was designed to gain insight into individual participant psychological worlds and is specifically a psychological research method. It could be argued that grounded theory is better suited to the identification of social processes that may account for phenomena and that IPA is concerned with gaining a better understanding of the quality and texture of individual experiences. IPA focuses on producing knowledge at the micro level of analysis, whereas grounded theory's focus lies at the macro level. In my research using IPA will enable me to produce in-depth knowledge and understanding of mothers' experiences of anxiety at the micro level of analysis. Gaining insight into the participant's world will increase our understanding of how anxiety is experienced and how it may be interwoven in the parent-child dyad. It will help us to make informed judgements

about what services families would most benefit from and how to tailor treatment programmes to accommodate children with ASD and anxiety.

2.7.3 The Narrative approach

IPA and Narrative psychology have much in common with IPA acknowledging the importance of the narrative. Narrative psychology is concerned with interpreting the meaning of the individual's narrative. Through reconstructing and telling their own narratives individuals are able to re-interpret their lived experiences (Eatough & Smith, 2008), and make connections between events (Willig, 2013). Whereas narrative research focuses on exploring the life of the individual, IPA's focus is on understanding the meanings underlying the individual's experience of a particular phenomenon. In this case, I was keen to explore the phenomenon of anxiety within families with a child with autism as opposed to exploring a more general narrative regarding these mothers' lives.

2.7.4 Thematic analysis

Although both IPA and thematic analysis use a similar method of analysis to analyse the data and identify emergent themes from the data, the methodologies differ in two significant ways. Thematic analysis is used to identify and interpret patterns of meaning across qualitative data, but does not employ the same idiographic approach as IPA (Braun & Clarke, 2014). Thus, when analysing the data, the analysis focuses on exploring patterns across cases and does not take into account the experiences of the individual. I was keen to analyse the data for each individual participant as well as exploring the data across all the cases. Secondly, thematic analysis is not aligned with a particular theoretical framework, but needs to be chosen by the researcher (Willig, 2013). I felt that IPA offered me the opportunity to explore mothers' experiences within a clear theoretical and epistemological framework and I that

IPA's philosophical underpinnings best served my research question. I also felt that my epistemological standpoint was best aligned with the use of IPA and the way in which I work as a counselling psychologist.

2.8 QUALITY OF THE APPROACH

As qualitative research becomes a more popular method of research, there is a continued need to demonstrate the quality of the ways in which the research has been conducted. Elliott, Fischer and Rennie (1999), together with Yardley (2000) provide a widely cited set of guidelines of how to achieve this within qualitative research.

Based on Yardley's (2000) set of principles I have attempted to explain the ways in which I am able to demonstrate the quality of my research. These are explained briefly below:

2.8.1 Sensitivity to context

Yardley suggests that sensitivity to context may be demonstrated through an understanding of the relevant literature around the topic, through providing a rationale for the use of IPA, and through demonstrating sensitivity to participants.

At the developmental stage of my study, I spent much time thinking about my research question, and how best to word my research question. This included thinking about whether I wanted to interview mothers, fathers, or parents and whether I was exploring the parent's anxiety, the child's anxiety, or both and how this might be played out within the parent-child relationship within the family. I needed to think about the question of anxiety, and what assumptions I might be making about anxiety within families where there is an autistic child.

Was I presuming that all children with autism experienced anxiety? Was I expecting the mothers to be anxious, and how might my presumptions influence the working of my questions and findings?

In developing my study, I focused on providing a rationale for the importance of my study and how my findings may help to further inform and develop the treatment of anxiety within ASD. In so doing, I have provided the context in which my study may be relevant and informative.

Sensitivity to context may also be demonstrated through the recruitment of a small, select homogenous sample of people who have shared a particular lived experience. In my study, this was of particular importance as I interviewed a small sample of mothers who I recruited through word of mouth. This meant that participants may know of one another, and I needed to pay particular attention to concerns regarding confidentiality and anonymity.

Sensitivity to context also refers to the way in which the interview is carried out by the researcher, with particular attention being paid to the researcher demonstrating empathy, warmth and understanding towards the participant. This sensitivity to context also continues into the way in which the researcher shows sensitivity to how sense is made of interpreting the findings. At the initial stages of developing my study, I received feedback questioning whose anxiety I was exploring (mothers' or the child's) and how might mothers experience my questions regarding their own anxiety, might they feel blamed in some way for the anxiety of their child? I decided to focus the question on the mothers' experiences of their child's anxiety, and included questions about the mothers own anxiety in relation to their child. Ethically, I took very seriously the feedback

that mothers could feel blame in someway for their child's anxiety, and that my research could exacerbate this.

2.8.2 Commitment and rigour

Yardley (2000) suggests that commitment within an IPA study can be demonstrated through the way in which the researcher carries out the interview, and the degree of attentiveness paid to the analysis of each case. In my research I paid particular attention to how I carried out my interviews, and was particularly mindful of my participant's emotional well-being during the interview. I was aware that the interviews may be emotionally difficult for the participants, and allowed time at the end of each interview to de-brief with the participants. During the analysis stage, I focused on trying to ensure that each of my participants' voices were heard and paid particular attention to which words I quoted that I felt would best represent each participant's response.

Rigour refers to the detailed attention paid to the selection of the sample, the way in which the interview and analysis was carried out (Smith et al., 2009). In the development of my study, I decided to focus on mothers' experiences of their autistic child's anxiety, as opposed to my original idea of interviewing both mothers and fathers, in order to improve the homogeneity of my sample. As mentioned above, I paid particular attention throughout the interview to what was being said, to demonstrating warmth and empathy, to ensuring that the participant was comfortable and to their emotional well-being.

In my findings section, I have used direct quotes from the transcripts to give the reader as much access to the verbatim script, and to allow the participant's voice to be heard. This will help the reader to understand the words upon which

my interpretations have been made, enabling them to question for themselves the meaning of the participants' responses.

2.8.3 Coherence and transparency

Transparency refers to the how clearly the researcher writes up the different stages of the research process. Throughout my study, I aimed to be as transparent as possible, providing as much detail as possible in my write up and analysis.

In demonstrating reflexivity, I have aimed to be transparent in the ways in which I may influence the study, and have included paragraphs in the methodology and discussion chapters regarding my personal reflexivity. Through writing several drafts of each chapter and seeking feedback on my write up, I aimed for my research to be as coherent as possible. Coherence also refers to the extent to which my research reflects the theoretical underpinnings of IPA and the degree to which I have been able to carry this out. I have aimed to demonstrate the rationale for using IPA and attempted to stick as closely as possible to the guidelines recommended for using IPA.

2.8.4 Impact and importance

Yardley (2000) suggests that validity can be demonstrated as the extent to which the study is informative for the reader. As discussed, counselling psychologists are gradually entering into the field of children and adolescent mental health and the role of the counselling psychologist is key in helping the parent to understand the relational dynamics with their child and the bi-directionality of their own and their child's anxiety. This research aims to contribute further understanding of the phenomenon of anxiety within autism to

the field of counselling psychology. If the study successfully explores this phenomenon, then it will be of benefit to all professionals working in this area.

2.9 LIMITATIONS OF IPA

Phenomenological research aims to understand the experience of the participant in order to produce rich detailed data of a particular phenomenon. A criticism of this approach may be that in doing so, it does not attempt to offer any explanation for what is causing these psychological events to occur. However it can be argued that by gaining insight into the subjective lived experience of these individuals, IPA will provide a micro analysis of individual experience which is currently missing from the literature. Further research can subsequently be done to examine possible psychological processes that may be causing or maintaining the role of anxiety within these families at the macro level.

IPA research is mostly carried out using semi-structured interviews. Phenomenological research can be questioned as to the degree in which participants are truly able to communicate the rich texture of their experience to the researcher (Willig, 2013). Language is the means by which participants attempt to communicate their experiences to the researcher. This method relies upon the representational validity of language (Willig, 2013). Discursive psychologists argue that language constructs rather than describes reality. They believe that the words we choose to describe a particular experience always construct a particular version of that experience. The same event can be described in many different ways. From this point of view an interview transcript might tell us more about the ways in which an individual talks about a particular experience within a context than about the experience itself. Arguably, IPA's focus is on understanding the meaning behind the experience of the

phenomenon rather than on the deconstruction of language and its focus will be hermeneutic, idiographic and contextual (Smith, 2004). Through the process of hermeneutics, IPA acknowledges that our experiences are interpreted through the use of language, and that experiences can be understood through our relationships with others, cultural and contextual underpinnings.

2.10 SUMMARY: WHY IPA?

In this study, IPA enabled me to explore mothers' experiences of anxiety within their family providing detailed, idiographic data from which I interpreted the meanings both empathically and from a questioning critical stance. There have been few qualitative studies exploring mothers' experiences of anxiety, and in particular the relational angle between the mothers' anxiety, child's anxiety and treatment outcome. IPA enabled data to be produced at the micro level of analysis providing in-depth knowledge about these experiences and their underlying meanings.

2.11 DATA COLLECTION IN IPA

The semi-structured interview is the most widely used method of data collection in IPA. The interviews are usually one-to–one and tend to last from 60-90 minutes. Questions should be open ended, and non-directive enabling the participant to lead the interview and focus on what they want to discuss (Smith, 2004, Smith et al., 2009). A disadvantage of using this method can be that the data collected may be dependent on the relationship between the researcher and participant and the extent to which the participant is able to speak freely and openly to the researcher.

Alternative methods of data collection that could be used are focus groups and single case studies. Smith (2004) suggests that IPA has been developed as a

method to produce in-depth and detailed analysis of participant's subjective and personal experiences and that the semi-structured interview is more aligned in doing this than a focus group. Tomkins and Eatough (2010) reflect on the use of IPA with focus groups and conclude that the focus on the group-individual dynamic in focus groups may represent a fundamental shift from the idiographic nature of IPA.

Smith (2004) argues an important area for development is the use of case studies in IPA. He suggests that if enough rich data is being yielded from a particular case then it is possible to push the idiographic logic further and conduct an analysis on a single case study. Warnock (1987) suggests that by delving deeper into the particular we also increase our understanding of the whole and can become better positioned to think about how we and other people might deal with the particular situation being explored.

My interest lies not in doing a case study, but in interviewing a small number of participants, so that I can understand their individual experience at the idiographic level as well as exploring patterns across cases. For this reason, I chose to interview seven participants using a semi-structured interview. This was in preference to employing the use of a focus group for two reasons. Firstly, I wanted to further build upon the work of Ozsivadijan et al.'s (2012) study on parental perspectives of anxiety, which had employed the method of focus groups in their research. Secondly, I was keen to retain an idiographic focus in my research and felt that the use of a focus group may move the analysis away from the individual to the group level as suggested by Tomkins and Eatough (2010).

2.12 DATA COLLECTION PROCEDURE

2.12.1 Recruitment

I recruited participants through a local primary school that has a small number of autistic children attending, and via the method of snowballing. Being a mother of three young children myself, I used my network to talk about my research and find out if people would be interested in participating in my research. I approached mothers of autistic children and each one was comfortable to participate in my research. Prior to the interview, participants were given a consent form to sign to indicate that they were willing to participate in the research. See appendix B for copy of the consent form.

2.12.2 Participants

I interviewed seven mothers of autistic children. The participants were all mothers of autistic boys aged between 10-16 years of age. Each of the children had been given a diagnosis of autism and one child had also been diagnosed with severe anxiety. The mothers all lived in London. Some of the autistic children had no siblings, and others had one or two siblings. Some children attended a mainstream school, others attended a special unit for autistic children within a mainstream environment and one child attended a residential home. Each participant has been given a pseudonym and details of their child remain anonymous to ensure confidentiality.

2.12.3 Pilot

The pilot interview gave me an opportunity to practice my interview technique. At the time I had not found a mother with an autistic child to interview, so I interviewed a mother whose child was experiencing anxiety. During the interview I was aware of how nervous I felt and this provided me with an opportunity to reflect on my feelings with regards to carrying out future

interviews. I was aware during the pilot that I did not ask all of the questions on the interview schedule, and tended to be lead by the interviewee. I became aware that it was more important to listen attentively to the participant, and focus on asking probing questions about their experience rather than being distracted by the interview schedule. As Smith et al., (2009) advise, following on from the pilot, I used the interview schedule as a tool with which to provide myself with some guidance and structure for the interview but did not feel the need to strictly adhere to it.

2.12.4 Semi structured interview

In constructing the questions for the interview schedule, I remained aware that I wanted my questions to be as open ended as possible to allow the participant to speak freely about their experiences. In developing the schedule I was aware of the need to begin by helping the participant to feel as relaxed as possible and thus opened up with some introductory questions inviting the participant to tell me about their family and child. The purpose of this was also to gather some background information to set the context in which their child had been diagnosed with autism, what had happened in the early years, and to then be able to lead the participant to tell me about what was happening in the current day. This enabled the mother to set the context from which she could go on to explain about her current situation with her child. Following on from the initial generalised questions, I wanted to focus my questions about the child's behaviour and feelings, and gather further information about how their child currently behaved, how they had behaved in the past and whether the child's behaviour had changed over time. I did not want to make assumptions about their child's anxiety, and thus asked about the feelings of their child prior to narrowing my question to focus on any anxiety the mother may believe their child to have experienced. I did not define anxiety for the mother, wanting to

understand from them how they experienced their child's anxiety, but was aware in my mind that I was conceptualising anxiety through possible changes in behaviour and the feelings and worries of the child. From asking about the child's behaviour and feelings I then felt able to explore how the mother experienced their child's anxiety, what it was like for them, and whether they had experienced anxiety or depression. I felt it important to then ask about their relationship with their child, wanting to understand whether their relationship with their child had changed over time, but also to give the mother an opportunity to discuss how she felt about her son, and to be able to focus on the positive qualities of her child. I ended the interview with questions about what treatment if any had they or had their child received and how they had experienced this treatment. My final question was to ask what would have been helpful for these mothers, this was particularly poignant for me in terms of informing the development of future interventions for children with autism and anxiety. I was aware of the importance of helping the participant to feel comfortable and encouraged them to talk about what felt appropriate to them. I wrote a list of prompt questions to remind me of probing questions I could ask to help the participant to expand on their answers. I sought feedback on the interview schedule with my supervisor and changed some questions accordingly, ensuring that they were less leading and more open ended. See appendix C for a copy of the interview schedule.

I interviewed seven mothers of autistic children varying from ages 10-16 years. For reasons of confidentiality all names and any identifying details of both mothers and children have been changed to ensure anonymity. All interviews were carried out at either my or the participant's home in a quiet and confidential space in which the participant felt comfortable to speak openly and freely.

Interviews lasted for 60-90 minutes and time was allowed for the participant to de-brief at the end of the interview.

2.12.5 Recording and transcription

I recorded each interview using a digital recorder and stored the recordings in both a locked drawer, and on a password protected home computer in accordance with data protection legislation requirements (BPS, 2010). I transcribed the interviews using software that enabled me to slow the pace of the dialogue and accurately transcribe the words verbatim.

2.13 PERSONAL REFLEXIVITY REGARDING THE DATA COLLECTION PROCEDURE

I was surprised at how easily I managed to recruit participants for my study and participants willingness to participate in the research. I wondered whether this was a reflection of mothers not previously having had the opportunity to discuss their experiences and their desire to do so.

Although I had expected that the interviews would be challenging, I had not expected to connect with my participants on such an intimate and emotional level. Perhaps they had previously not had the opportunity to speak in this way to someone, certainly the impression I had was that they have received little support over the years, bearing the full responsibility for their child themselves. I was aware when interviewing of the fine line between my role as the interviewer and my role as therapist, and I was keen to not take on the role of therapist in these interviews. Instead, I focused on using the skills that I have learnt in training to ensure that my participants felt listened to and supported throughout the interview.

The interviews felt highly emotional, and the debrief at the end of the interview enabled us to discuss in a less formal manner how the mother had felt about the interview process. The mother was often surprised at how emotional and drained she felt at the end of the interview and the debrief was essential in allowing the mother space in which to discuss some of these feelings and provided an opportunity to discuss ways in which further support could be accessed if needed. On reflection, it may also have been beneficial at the end of the interview to reflect with the mother on the positive qualities of their child, focussing on their child's strengths all of which the mothers spoke of at points during the interview.

2.14 ETHICAL CONSIDERATIONS

I thought carefully prior to developing the research about the ethical implications and the sensitivity of the issues that would be discussed. My thesis adheres to the BPS code of ethics and conduct (2010) and prior to beginning the research, I obtained ethical approval from City University to go ahead with the project (see appendix E). Participants were given an information sheet prior to the interview explaining what will be involved in the research and that they could leave the process at any point should they so wish (see appendix A). Informed consent was gained from participants at the beginning of the interview and I explained that the interview was confidential and any identifying details would be removed from the thesis (see appendix B). Confidentiality was adhered to throughout the process, with all identifying names, ages, being removed from the transcript. All documents with identifying details together with the transcripts were password protected and the recorder was kept in a locked drawer together with any documents containing identifiable details such as the consent forms.

Although this is a low risk population, I was aware during the interviews of how emotional it was for the mothers. I made sure that we had time after the interview had been recorded to discuss how the mother felt and to de-brief (see appendix D). At the end of the interview, I recommended books that I thought might be helpful and ensured that the mother felt able to access additional support if need be.

I was aware that the process of interpretation could be influenced by my own expectations and experiences of motherhood. I continued to identify these through the process of self-reflection. I was aware that my interpretation in the analysis is of a subjective nature and could be interpreted differently by other researchers. In writing up the analysis, I was also particularly conscious of the sensitive nature of what the participants had discussed and the need to ensure that there was no blame being placed on any mother for the child's anxiety.

2.15 DATA ANALYSIS PROCEDURE AND REFLEXIVITY

Using the method of IPA, the data was analysed following the steps outlined in Smith and Osborn (2008). This served to provide structure in helping to analyse the data and gave a degree of flexibility in the way in which I was able to approach the analysis.

Step 1: Reading and re-reading the transcripts

The first step consisted of transcribing the interviews and all names of participants were changed to ensure confidentiality. To protect and maintain confidentiality each participant was renamed participant from 1-7. However, on reading my analyses I felt I couldn't connect with the mothers in this way, so opted to give them a pseudonym instead.

After the interviews, I made some notes about what stood out for me from the interview and as a way to help me process what I found to be emotionally charged and draining interviews. For example, after my fourth interview I noted that I came away with the sense of the Mum believing that she should know what to do, and I had a real sense of her helplessness and lack of power in how she felt she should manage her situation.

The process of transcribing the interviews felt to be an important one as it enabled me to re-immerse myself in the data, and listen out for the emotions, the pauses, the tone and volume of the participant's voice. I found myself wondering at this stage how I would be able to portray a true sense of the participant's account in my findings.

Step 2: Initial noting

Initially I read and re-read the first transcript and begun to write notes on the left hand side of the margin. Smith et al., (2009) suggest that one way in which to begin this step is to go through the transcript making notes on what seems important and to also free associate from the participant's text. I found this a helpful place to begin and initially underlined sentences and words that stood out to me and then commented on why I had underlined them. I also used the method of free association at this point, writing down things that came into my head about what the participant had said. I then revisited the transcript a second and third time, underlining additional things of interest in black that were of a more descriptive nature. I used red ink to analyse the transcripts on a linguistic level and green on a conceptual level (see appendix F). Following this, I listed together some initial notes based on the comments made from the transcript (see appendix G). I kept questioning myself as to whether I was analysing in enough detail and found interpreting at a more conceptual level the most

difficult. This was reflected in my initial drafts in my analysis which at this stage I believed were too descriptive and needed further analysis at the interpretative level. In trying to stay as true to the participant's account as possible, I may have relied too much on their words and in describing their experience. I thus spent much time focusing on developing a more interpretative stance to help me to increase my understanding of what the underlying meaning of their experiences may be for these mothers.

Step 3: Developing emergent themes

I began to develop my ideas around the emerging themes by listing out all possible ideas. This stage felt hugely overwhelming as there seemed to be so much information and I found it difficult to find a way in which to break it down and cluster ideas together. After listing my thoughts around the transcript, I tried to group similar ideas together under headings. I felt frustrated that this did not seem to give credit to the depth of the participant's experience and I felt as if I was missing out some of the essence of the interview.

In this stage, I felt that there were clear messages coming through from the transcript that I wanted to convey, but so many themes overlapped, I was unsure of how to structure the ideas. Themes such as the sense of relentlessness, the loss of control, the need for their child to be understood all spoke volumes to me and I found it difficult to separate the themes from one another. (See appendices H and I).

Step 4: Searching for connections across emergent themes

I explored my clusters of themes that had emerged from my analysis of the transcript. I used mind mapping to try to focus my ideas and as a way of connecting my ideas and thoughts together. At this stage, I really reflected on

what the underlying meaning may be for the participant, and what message the mother might be trying to tell me through her narrative and how she made sense of her experience.

I felt overwhelmed by where to begin with all the data and how to best connect the themes that seem to be emerging in each transcript. There seem to be so many sub themes and patterns emerging that I have found it difficult to know where each sub theme best belongs. For example does the sub theme sense of helplessness come in the cluster of mothers' feelings, does it represent a theme on its own, or is it part of an alternative theme such as that of control?

I explored the frequency in which some ideas seemed to be repeated through the analysis such as the sense of helplessness and looked for patterns and relationships within and between the themes. For example, the sense of helplessness and lack of choice which one mother really conveyed to me, contrasted with her decision to ensure that her son attended school no matter what. It seemed relevant to explore what might contribute to the mother being able to enforce her will in some areas of life but not in others.

I continued to reflect on this step, and although had lists of emerging themes, continued to play around with how to cluster them together and what I felt best represented my sense of the participant's experience. (See appendices J and K)

Step 5: Moving to the next case
The next step in the analysis involved starting again with my next transcript. I left at least a week before beginning the process transcribing my next interview to allow me time to process my thoughts from the first interview and to try to bracket my ideas from the transcript that I had just finished. This was an attempt

to allow new themes to emerge from the next transcript and to be aware of what might influence me from the previous transcript. I then followed the steps outlined above for each new transcript.

Step 6: Looking for patterns across cases

This step was hugely frustrating and overwhelming. I found it difficult to know where to begin in drawing connections between the cases, and although there were clear themes emerging across the cases, it was difficult to know what to include and what not to include. I wrote several different lists to represent my ideas and in doing so came up with themes that again overlapped and could be written in several different ways. I drew up a table illustrating the development of emerging themes (see appendix L). Following this, I drew up different versions of master tables that enabled me to reflect on the ways in which the emerging super-ordinate and sub-themes could be represented (see appendix M).

The theme of "loss of control and helplessness" in my findings lead me to reflect on my own relation to control particularly in terms of how out of control I felt in trying to analyse the data and give voice to the participant's accounts. I felt helpless in deciding which quotes to include and overwhelmed by the amount of data. In focusing on the participants who spoke out the most powerfully to me, and constantly referring back to my research aims, I gradually began to feel less helpless, and in greater control of the analysis and the emerging themes.

After writing my first draft of the analysis, I felt dissatisfied with the way in which I had categorized the subthemes under the superordinate themes. Feedback suggested that my draft analysis focused too much on describing the child's behaviour and not enough on the mothers' experience. I thus spent time re-reading each transcript paying particular attention to trying to pull out the

mothers' experience and what I felt they were trying to tell me throughout the interviews. Furthermore, I became aware that my initial analyses reflected not only the mothers' experiences of their child's anxiety but also their child's autism. I did not want to be seen to be exploring two phenomena, my aim being to explore mothers' experiences of their autistic child's anxiety. However, anxiety and autism being intertwined, I struggled with how best to focus my findings. I spent much time reviewing my analysis, and tried to ensure that they reflected the mothers' experiences of anxiety. I decided to keep some subthemes such as "uncertainty about the future" which did not solely relate to the mothers' experience of their child's anxiety, but also to their child's autism, as the themes seemed too significant not to include. I re-wrote the names of each theme, cutting them out on pieces of paper and playing around with the different ways in which they could be linked together. I finally drew up a new table of themes that I felt was more representative of the mothers' experiences. My final draft of analysis was based on this new table of themes (see appendices N and O).

2.16 SUMMARY

This study used IPA to explore how mothers make sense of their child's autism and anxiety in order to inform the development of future treatment for anxiety in children with ASD. The intrinsic nature of IPA is its focus on understanding an individual's experience and how they make sense of this experience (Smith et al., 2009). IPA is influenced by three key areas of philosophy of knowledge, namely that of phenomenology, hermeneutics and idiography and draws upon these theoretical approaches to inform its epistemological framework (Smith et al., 2009). The role of the researcher in IPA is implicit in interpreting the data. Double hermeneutics refers to the ways in which the researcher is trying to make sense of the participant trying to make sense of their experiences

(Shinebourne, 2011). The process of reflexivity forms an essential part of IPA and enables the researcher to reflect upon the ways in which he/she may influence and impact the process of research and its findings (Finlay, 2008).

The phenomenological approach underpins IPA and focuses on generating understanding about the subjective experience of the individual (Smith et al., 2009). IPA subscribes to a relativist ontology, suggesting that there are multiple ways in which the individual might experience a given phenomenon, and aims to understand the meaning of the individuals subjective experience (Willig, 2013). Given the influence of symbolic interactionism within IPA the researcher also needs to be aware of how the relationship with the participant may influence the outcome of their research (Willig, 2013).

In this study seven mothers of autistic children aged between 10-16 years were interviewed using a semi-structured interview. Participants were recruited through a local primary school and through the method of snowballing. All identifying details of participants have been changed to ensure anonymity and confidentiality. Data was analysed following the steps outlined in Smith and Osborn (2008). This study adhered to the BPS code of ethics and conduct (2010) and ethical approval was gained from City, University of London.

CHAPTER 3: FINDINGS

3.1 INTRODUCTION

This chapter describes three super-ordinate themes together with their subthemes that have emerged from the data. I am aware that these themes are my interpretation of the data, and that others may have interpreted this differently. I have attempted to draw out the quotes that really struck me, and not every participant has been represented in each section. Where appropriate, I have contrasted the mothers' different experiences with one another. The master table of themes can be found in appendices N and O.

The first theme is titled "Mothers' internal struggle" and includes three subthemes: mothers' inner turmoil, their fight for help and the relentlessness of living with their child's anxiety. Underlying these subthemes is the mothers' struggle to do their best for their child and the exhaustion they experience in trying to do so.

The second theme focuses on the mothers' sense of loss of self that seems implicit in the ways in which the mothers adjusted their lives to adapt to their child's anxiety. The subthemes balance of power and unpredictability draw upon how the mother experiences the ways in which her child exerts his influence and control within the family.

The third theme draws upon the overwhelming sense of tensions that the mother seems to experience in parenting her child with autism and anxiety. The subthemes self-blame, the desire for harmony within the home, the desire for acceptance and uncertainty about the future, suggests the extent to which the mother takes on the responsibility of worrying about her child.

With the use of each quote, I have attempted to convey the essence of the mothers' experience of their autistic child's anxiety. "…" indicates that the participant has paused, and [..] indicates words missing in the transcript.

3.2 MOTHERS' INTERNAL STRUGGLE

The mothers seem to experience internal dilemmas regarding how best to manage their child's anxiety. Underlying this seems to be the all encompassing role of motherhood in which the mother strives to do her very best for her child, questioning herself in the process. The mothers conveyed their struggle to access appropriate support, and the extent to which they found living with their child's anxiety as relentless and all consuming. Living with the constant inner turmoil served to exacerbate the exhaustion that these mothers feel.

3.2.1 Mothers' inner turmoil

Underlying the mother's angst seems to be their overwhelming desire to be able to "fix" their child's anxiety, their struggle of not knowing to what extent they should challenge their child at the cost of seeing their child's distress and the painful choices that they make for the sake of their child.

Emily states that *"because I'm his Mum, I should be able to do everything for him.." (p.15, 729).* This suggests that there is the expectation that in her role as Mum, she should be able to "fix" the problem, and is aware in not being able to do so of her son's anger and frustration towards her. The word "everything" suggests the extent to which Emily's perception of motherhood is all encompassing, and one in which the mother's responsibilities are limitless. In not being able to fulfil her expectations of herself as a mother, she may feel

increasingly frustrated leading her to doubt her competency as a mother. Emily's frustration may lead her to believe that she is failing her son in some way.

"..I think he feels that he wishes I could do more to stop his thoughts (p.15, 721) […]… which is really frustrating for me and for him, because I'm his Mum, I should be able to do everything for him. You know he gets frustrated that I can't help him and angry that I can't help him…" (p.15, 729)

Emily also says *"..because I wish I could get into his head and pull those worries out, but I can't.." (p.15, 722)*

The word "wish" emphasises her yearning to be able to take away her son's mental anguish, something that she is not able to do. Emily would physically like to "pull" the worries away, perhaps symbolising the strength of her desire to help her son, leaving her feeling frustrated in her inability to do so.

Ellie spoke of not knowing how to manage her son's anxiety believing that there was seemingly no answer to resolve it. Her sense of desperation in not knowing how to help her son is evident and perhaps exacerbated in the belief that she should be able to resolve her son's difficulties. Her son's fear is perhaps contagious, with Ellie becoming increasingly desperate and fearful herself in not knowing how to find a solution for her son.

"..we were really quite desperate, it was completely taking over our lives.." (p.2, 62).

Ellie spoke of having "no choice" which perhaps suggests that in her role as mother, she feels there are no options, and bears full responsibility for caring for

her son. As a mother she perhaps believes it is her role and duty to be able to "fix" and resolve her child's problems and subsequently feels a constant anxiety in being unable to do so. The uncertainty of how best to help her son leaves her feeling anxious and frustrated in her desire to protect her child from experiencing this pain.

"..and I know that sounds like we should have been able to do something about it but it's been impossible to (p.16, 727)…[..]. I don't know..and when you look at the anxiety he goes through, I don't know what you're meant to do about it..(p.16, 732) [..]..I've found it really hard at times, really really hard..umm…but it's well..I don't really have a choice..sighs umm.." (p.16, 743)

It seems that her son's anxiety plays into the mother-son relational dynamics, with Ellie feeling in a permanent state of worry and anxiety. His anxiety becomes her anxiety and Ellie's difficulty separating herself from her son's distress is evident.

Ellie spoke of how she has found a way to help her son contain his anxiety, and suggests that there has been a balance in deciding how much anxiety she is willing to see her son experience. Again, she speaks of the dilemma in wanting to do her best for her son, and the need to balance this with how much pain she is able to witness him experiencing and the benefits of doing so.

"..we've let him get away with more because we can't keep up that level of making him do things..(p.17, 806)..[..]..it's not necessarily the best, but then I don't think it's the best to have him always feeling ….tensions.." (p.17,815)

The question of how much to "push" her son arises and it seems that Ellie is grappling with the extent to which she feels able to do this, feeling responsible for the anxiety that her son subsequently experiences and unable to bear the extent of his pain. The struggle within herself may reflect the struggle that she has with her son, the need for her own life at the cost of seeing the anxiety her son then endures. Here, Ellie speaks of how she and her husband no longer go away on family holidays, it being too anxiety provoking for her son to be away.

"..it was more unbearable being away.. [...].. He could not stand it, [..].. just found it so unbearably anxiety provoking and we used to just push it and go, but the last time I think we just thought we can't do it". (p.15, 182)

Similarly, Charlotte questions the extent to which she should challenge her son, worrying that he could be achieving more but fears the consequences of doing this would be to increase his anxiety. It seems a balancing act of how far to push her son and how much distress and challenging behaviour she is able to cope with.

"..you see some parents who are constantly trying to help their child and tutoring and one-to-ones [..] and I probably should do more of that but then he'd probably be more anxious, I probably should do more..there's always that guilt isn't there" (p. 10, 465)

The repetition of the word "probably" suggests Charlotte's questioning of herself as to whether she should challenge her son to a greater extent. It seems her instinct is to not challenge her son enabling him to function at a level that he is comfortable with. This is further demonstrated when Charlotte spoke of creating a safe environment at home for her son in which he did not feel challenged. The

word "guilt" suggests that she feels that whatever she chooses to do won't necessarily be the right choice. If she challenges him more, perhaps she will cause him to become more anxious, by not challenging him enough perhaps she isn't helping him to reach his full potential and capability. Underlying her internal dilemma seems to be the question of how far she should challenge her son and what the implications for her son, herself and her family would be in doing so.

Grace reflected on the ways in which she tried to help her son manage his anxiety, through reassurance, preparation, support and focussing on his needs.

"..I'm not picking up on the anxiety of him, as soon as he has ..something then I'll try to fix or try to deal with it..". (p.7, 345)

The words "fix it" again suggest that like the other mothers, Grace believes she should be able to resolve her son's issues and get rid of his anxiety. It seems that she believes it is her responsibility to do this.

Grace went on to speak of her own issues of anxiety, and described her own struggle with anxiety and her desire to protect her son, coupled with her desire to see her son reach his potential through experiencing new and challenging situations. The need to protect him yet allow him to engage with new experiences is anxiety provoking for Grace, and she, like the other mothers, questions to what extent she should push her son do things outside of his comfort zone.

"..hard for me as the anxious parent to put him into situations where I'm not protecting him..[..]...it's me that has the anxiety for him..but I don't think..I don't sense that he is a particularly anxious person.." (p.10, 482)

Anna spoke of her desire for her son to be happy, and wanting to support her son in his decisions. However, in doing so, Anna felt torn, seeing how her son's decisions did not result in his happiness. There is the sense that Anna feels she should be able to "fix this and make her son happy". Her laughter is perhaps reflective of her deep inner pain of believing that her son is not happy and her desire as a mother to do everything that she can to ensure her son's happiness. It seems that she is trapped in wanting to support her son, and enable him to make his own choices, but at the same time then has to experience his pain in doing so.

"..which in some ways I think well good for you, be yourself and be happy. But he's not very happy…" laughter (p.9, 446)

Anna suggests that she avoids having the time to stop and reflect and to be alone with her thoughts for fear of experiencing the deep pain that has become her life. The words "go mad" suggest the extent to which she would be distraught, perhaps losing control of her emotions if left alone to contemplate how she really feels.

"I keep really busy, I cant really just sit and do nothing because otherwise I would go a bit mad.." (p.9, 458)

Amy spoke of how she made the decision for her son to leave the family home and to live in residential home. She described the decision as a "heart-breaking inevitability", implying that she felt she had no choice in doing this.

"you know coming to terms with him having to go away to school..it was like a …heart-breaking inevitability…and felt a lot of guilt around that…I know it was the right thing to do because I know it was the right thing for him...." (p.16, 770)

Amy came across as in no doubt that this was the "right" thing for her son and for her family. The words "heart-breaking inevitability" suggests the depth of pain Amy felt in accepting that she was unable to look after her son at home. The "guilt" suggests the compromise that she has had to make as a mother for the sake of her son and her family. Amy seems to know the choice she felt forced to make was the best outcome for her family, but felt deep pain in having to make this decision. The guilt may stem from her belief she could no longer fulfil her role as a mother in the way that she would have liked, but felt that she had no option but to compromise her desires in her wish to do what was best for her son and for her family.

Amy's need to balance her own desires with that of her child's needs are evident in her acceptance that she could not continue to look after her son at home. The word "sustainable" suggests the extent to which Amy felt unable to continue living with her son at home and the struggle she endured in trying to accommodate her son's needs in the home environment. The "pull" between wanting her son to be at home, and the recognition and acceptance that her son did not fit into her world is evident, with Amy prioritising his needs and happiness.

"…life was not sustainable…you try sometimes, if you try so hard to pull your child into your world and actually (my son) doesn't belong in our world, he's got this little world where he's happy and I think we need to respect that.." (p.8, 405)

3.2.2 Fight for help

The mothers also spoke of their fight to access help for their children, and when they were able to access support, faced the difficulty of their child not being able to engage with the support offered. In not being able to access the appropriate support for their child, these mothers were perhaps left feeling uncontained in their own anxieties, in the same way in which their child may feel uncontained. The mothers' capacity to manage their internal worries may have been reduced as a result of their uncertainty in knowing how to manage their child's challenging behaviour and the subsequent lack of help and support in helping them to cope at home. Their sense of desperation and fight to access help for their child is evident, and their ensuing feelings of isolation apparent in their attempt to cope with their situation.

Ellie spoke of her attempts at reaching out for support for her son and her feelings of desperation in not knowing how to help him. Her continued and repeated attempts to access help may have increased her anxiety and fear of not knowing how to manage her son at home. Underlying this seems to be an increasing sense of despair and isolation in her struggle for support for both herself and her son.

"..and the consultant told us that if he was diagnosed with Asperger's he wouldn't have any help.. because there's no point in giving help to anyone with Asperger's in terms of the anxiety (p.4,161)

"..so I kept getting in touch with them, please we really need some help because he was completely beside himself much of the time…" (p.4,179)

Once Ellie accessed help for her son, she spoke of the difficulties in being able to make use of it as her son was too anxious to attend and unwilling to engage.

" ..then we started going to CAMHS…but he didn't engage, he didn't want to go, he and that's the other thing, he finds it so stressful, just the idea of going, you then question whether it's worth it.." (p.10,466)

Again the question of "whether it's worth it" arises. In seeing their children experience the anxiety, the mothers are left questioning to what extent they should push their child against their will. Ellie's inner struggle of how to best help her son at the cost of seeing the extent of her son's anxiety is evident here. The pain of seeing her son experience such duress meant that Ellie was left again not knowing how best to help him. Ellie may have been unable to tolerate her son's pain, in the same way that he was unable to tolerate his anxiety. It may have felt preferable for Ellie to stop pushing her son to go to therapy in order to relieve both her son's anxiety and her own stress and discomfort in seeing him in such distress. This may have then resulted in Ellie feeling a loss of hope and increasingly isolated, not knowing what intervention if any would be available to her son and her family.

Some of the mothers spoke of how when help was made available, their son was unable to engage with the therapy. The mothers suggested that their sons needed the constant reinforcement of any strategies discussed in therapy on an ongoing basis for them to be beneficial for him.

"when he was in a state we really wanted help for him, but actually when it came down to him getting help he wasn't able to use it, because it's like unless you do something so many times, he cant get a grip on it" (Ellie, p.10,480)

"I don't think you can it on a once a week basis with him, it sort of has to be an ongoing thing which he's got at school.." (Charlotte, p.15, 764).

The mothers received little support for themselves in helping them to manage their child's anxiety. There is the sense of isolation, that these mothers were alone in trying to help their child manage the anxiety, and alone in managing their own distress.

"it was good to sound off…[..]..i think it was at a time when I was feeling very very stressed, it was right to be able to kind of unload and stuff..[..]..but it didn't take me any further forward with him.." (Ellie, p.17,786)

"..not really, I mean, I have my friends, I don't like talking about it too much.. no-one likes to hear.." (Emily, p.11, 528)

"..and I still think..our biggest thing was that nobody kind of supported us..with dealing with his violence.." (Sophie, p.14, 732)

Sophie spoke of how in all the time that her son had been increasingly violent towards her she had not received any support in how to manage his behaviour. Her anger towards the professional services and distress in being alone in dealing with his behaviour is evident. It seems that the mothers felt unsupported in trying to manage their child's anxiety. When help was available, their child

may have been unable to engage, perhaps further exacerbating the mothers' sense of helplessness and isolation.

3.2.3 Relentlessness of living with their child's anxiety

The mothers spoke about how they experienced their child's anxiety as all encompassing, perhaps using up all of their internal energy in the same way that it does for their child.

Sophie spoke of her exhaustion in managing her son's anxiety. It seems that there is the expectation from both her and her son that she will be there to support her son one hundred percent of the time regardless of her own needs. The use of the word *"constant"* and *"there's always something"* reflects how it may feel endless and never ending.

"..so it's exhausting our day because …it's not like he he just goes off and reads for an hour…it's kind of this..constant umm I have to go in there, (my husband) has to go and then he'll call again, and then he'll start talking..about what he's worried about the next day..umm and there's always something.." (p.19, 1022)

Sophie spoke of her anxiety at knowing that once she returned home from work the evening was going to be "horrific" and her desire to not have to deal with the situation.

"…we kind of used to go to work every day and then come home knowing that the evening was going to be horrific again…I remember sometimes I used to think like I almost used to wish I was ill, I would be ill so that I wouldn't have to deal with it" (p.15, 808)

The desire to be "ill" suggests the mothers' need to escape. The worry about what was to happen at the end of the day and the inability to prevent it from happening, suggests that she may have felt trapped with no way of escape. Sophie's helplessness and exhaustion in trying to manage her son's behaviour left her in desperate need of a break.

Ellie spoke of how her son's anxiety can take up all of her time and how she finds it exhausting. Ellie spoke of how she finds it difficult to have time for her own internal thoughts as her son needs constant contact with her.

"…I mean it was just, it's so encompassing when he's anxious […], takes up every second of every day with him telling you he's anxious, it's all getting in a state, having tantrums.." (p.6,286)

It seems that in dealing with her son's anxiety there is little room for her to separate from her son and have time for her own thoughts. Ellie experiences her son's anxiety as relentless and all consuming.

"you can't ever be worried about something yourself or thinking about something yourself because he needs this contact with you a lot of the time and then it's very hard to have your own thoughts. So then, I ended up getting cross…and aagh…" (p.12,572)

Similarly, Anna spoke of the need to provide constant emotional support to her son and the extent to which it drives her "a bit mental", with her feeling in a constant state of stress. Her feelings of being on edge, and constant worry may mirror her son's continuous anxiety, and in the same way that his anxiety seems endless, this mothers stress is also interminable. As long as her son continues

to be anxious and worry, Anna is unable to relax herself in her awareness that her son's anxiety is limitless and that as his mother, she will always be there to witness and endure it.

"…it's like you can't talk to me anymore today..we'll start again tomorrow, because actually I start to go a bit mental.." (p. 6, 289)

Emily reflected on her need to have time to herself, the constant demands of looking after her child seeming never ending. The extent to which she has given herself over to the demands of caring for her son leaves her feeling empty unable to deal with the company of others and any demands that may make on her.

"..it's draining, it really is draining…so it has affected our marriage… it's constant, it really is constant. At the moment, my evenings, I don't even want to be with my husband, I just want to be on my own…." (p.19, 919)

3.3 LOSS OF SELF

This theme includes the sub themes balance of power and living with unpredictability. Linking these subthemes are the ways in which the child may unknowingly be trying to achieve control of their environment, and the subsequent powerlessness that the mother may feel in managing her child's behaviour and family life. The mothers seemed to experience a loss of sense of self in their need to adapt to their child's anxiety together with an underlying fear of provoking an unwanted emotional outburst from their child.

3.3.1 Balance of power

Mothers spoke of the ways in which their lives were disrupted as a result of their child's behaviour. The desire to lead a normal life was thwarted by the need to adapt to their child's anxieties. These extracts begin to portray how family life has become fragmented, how the mothers have felt the need to allow their child to exert control over what they are prepared to do to make their lives more manageable. Consequently, the mothers seemed to experience a sense of loss and helplessness in trying to manage their child's anxiety.

In families in which there were siblings, the mothers spoke of the ways in which the families were often split, unable to spend time together as a family. The mothers may have felt compromised in their desire to spend family time together, feeling unable to force their sons to go out against their will. Again, the mothers' decision to compromise their wishes in order to adapt to their sons' needs is apparent. In doing so, the mothers may have experienced a sense of loss, adjusting their expectations of how they might have imagined and desired family life to be, and accepting the limitation that their child's anxiety imposed upon the family. The mothers may have felt they had little choice over what they ideally would have liked to do, fearing their child's response. Consequently, the children were able to exert their influence within the family and control the ways in which the family were able to spend time together.

"..it's like one of us with (my son) and one of us with the others because actually to try to do something with all of us is…[…]…horrible, I mean (my son) just hated it went screaming and shouting.." (Anna, p.13, 611)

"..unless he wants to go somewhere, I can't take her…" (Sophie, p.20, 1049)

Sophie likened her son's behaviour to that of "a wild animal", bringing images of a child raging against his parents unable to contain his anger and anguish. Sophie refers to her underlying helplessness in being able to calm her son down when he was in a violent mood. She was physically over powered by her son, and felt unable to protect herself against his rage. There is the sense in this quote of Sophie feeling that no-one could help her, and that she experienced a loss of power and control when faced with her son's violence.

"..once he was agitated and aggressive there was nothing, nothing could calm him own..(p.12, 639).[….]…when he was in a rage, he was properly strong, stronger than me, I couldn't fight him off, that was hard sometimes, he used to just kick me and punch me and like there's nothing I could do about it.." (p.13, 671)

Sophie described her situation as *"living in a house where there was domestic violence for a year.."* and again speaks of there being *"very little you can do".* The use of the words "domestic violence" implies that Sophie felt she was a victim and helpless in stopping her son's rage at home. The balance of power between parent and child seems to have once again been reversed with the parent being powerless in being able to defend against the violence. In being a victim, Sophie may have experienced being afraid of her son's anger, and fearful for her family's safety. She may have felt helpless in knowing how to manage his behaviour and scared of what the outcome of his aggression could be.

"…it's like we were…living in a house where there was domestic violence for a year which..it …(p.13, 713) [..]....and there's very little you can do…." (p.14, 724)

Sophie spoke of how she felt constantly sad and anxious during this time and was unsure of how to keep going, the situation having gone on for so long. In not knowing how to manage her son's behaviour, Sophie may have experienced a loss of hope that the situation would improve exacerbating her underlying anxiety and distress. Her lack of control in being able to prevent the violent outbursts may reflect her son's lack of control in being able to manage his emotions.

"you know there was, it was constant feeling of worry and sadness…(p.16, 848) [..]..anxiety and just..you know worry and then feelings of kind of umm..you know like..I don't know what to do anymore..cos it was months and months and months of it…" (p.16, 854)

Ellie felt "like she was under house arrest", the words symbolising her underlying feelings of loss of power and control within her life. Perhaps, also the loss refers to the loss of freedom and loss of self that she now experienced as a mother. Amy also uses the work "prisoner" to describe how she felt unable to go anywhere as a family and is indicative of the loss of freedom that she too experienced in her life.

"..every holiday I used to feel like I was under house arrest and he didn't want to come out so I'd force him out [..] we didn't go anywhere, we didn't do anything.." (Ellie, p.15, 713)

"it was just horrific. It was awful, life was …we were literally …I don't like to use the word prisoner because that just sounds awful…." (Amy, p.4, 18)

Ellie questioned the extent to which she should force her son to do things against his will, when his subsequent anxiety was so severe. In questioning whether it is "fair" to "force" her son to do things he didn't want to do, it seems that Ellie is questioning to what extent she "should" exert her control over him and at what emotional cost to him and for her.

"…I really don't know what you're meant to do.[..] because if you could see how physically ill it makes him ..[..].. is it fair that we force..you know he can't have his whole life feeling like a nightmare…" (p.16, 756)

Ellie's loss of self is perhaps reflected below in the way in which roles seem to be reversed. It seems that Ellie has become dependent on her son's permission to leave the house. In asking her son's permission, her son controls what his mother feels able to do, thus relinquishing her power, control and choice.

"..so anyway a year ago I started saying "can I just go and get a paper please?"….so he started some days letting me get a paper,.." (p15, 719)

In contrast to the powerlessness that the mothers may have felt in experiencing their child's anxiety, the mothers experienced being in control of ensuring their son attended school. It seems that the mothers were clear that they could not compromise over this and gave their son no choice. It may be that by having this rigid rule the mothers were able to exert their control in ways that they felt unable to in other areas of family life. It may be that they felt so strongly that their sons' attendance at school was not optional, that there was no internal dilemma for them, they believed they were making the right decision in forcing their son to go. It seems that the mothers felt they would lose all future power and influence over their son if they did not attend school.

"..he always went into school [..]…cos I thought the minute we say to him "ok, don't go", that will be it.." (Sophie, p.8, 422)

"..I just felt so strongly that if I had an 11 year old telling me they're not going to school then what am I going to do. If he stops at 11, then I haven't got a hope. So he had to go as far as I was concerned.." (Ellie, p.13, 607)

These mothers have had to adjust to living with their child's anxiety and in doing so have had to compromise the way in which they would ideally liked to have functioned as a family in order to accommodate their son's needs. In doing so, they experienced a sense of loss, loss of their self, their freedom, and their expectations of what motherhood would bring. In adapting to what their child is able to manage, they have experienced less control and less choice in how they feel able to live their lives and in their roles as mothers.

The balance of power seems to waiver between the mother and child, in some instances the mother chooses not to force her will over that of her child's perhaps fearing the emotional consequences of doing so and feeling unable to witness and manage his subsequent distress. In some instances however, the mother does feel able to exert her influence over her child, and it seems that she experiences being in control when the perceived consequences of not exerting her will would be detrimental to herself and her child despite the anxiety that he consequently experiences.

3.3.2 Living with unpredictability

This sub theme portrays the unpredictability of their child's behaviour that the mothers lived with. Life was described as "living with a time bomb", the knowing that any moment something might happen which was out of their control, and

there could be an explosion. There is a sense of the mothers' underlying fear in living with this unpredictability and of not knowing when their child may next have an outburst.

Anna is aware that she needs to choose her words carefully and control what she says. If she uses the wrong word it can lead to her son having a "meltdown". The uncertainty of how her son may react to her use of words may heighten Anna's stress and anxiety that she experiences in looking after her son.

"…and if I say the wrong thing it can lead to a massive meltdown…screaming tantrum fit, slamming doors, and then I worry…and that's the kind of thing you have to get, that if you use the wrong word you can get a meltdown.." (p.6, 298)

Anna goes on later to say *"I'm on the verge of a breakdown really…"* (p.9, 457) which suggests that the underlying tension in not only having to be careful and controlling in what she says, together with the constant stress that she feels in looking after her son leaves her feeling ready to collapse and unable to continue managing the constant tension and stress in her life.

Sophie felt there would "always" be something not right, but did not know what it would be. Underlying this may be Sophie's fear of knowing that she would be unable to prevent and control her son's emotional and physical response to a given situation. This may leave her feeling anxious and stressed in anticipating his reaction but not knowing what might provoke him at any point in time.

"..you can't predict either..umm..what's going to make him annoyed sometimes.." (p.19, 1010)

Like Anna, Sophie spoke of how she has learnt to communicate with her son on his terms, and seems frightened of communicating in the wrong way for fear of provoking her son to have a meltdown.

"…I suppose we have..kind of understand now ..umm when to leave him alone, umm when it's ok to talk to him, when it isn't..when he gets home from school, you cannot, you can't even say "how was your day?, nothing, nothing, absolutely nothing.." (p.18, 980)

The repetition "nothing, nothing, absolutely nothing" emphasises Sophie's fear of her son's response if she says the wrong thing. It seems that Sophie has learnt to accept that she can only engage with her son on his terms when he is ready to do so. There is the sense that Sophie accepts her son may always experience high levels of anxiety, but an underlying fear of not being able to cope when his behaviour becomes violent. Sophie may feel constantly anxious and fearful, feeling that she will not be able to cope if her son does not remain calm, therefore she must be careful of how she communicates with him and do everything within her ability to maintain harmony in the house.

"..but you can cope you know..it's you can cope when he's not..when he's calm.." (p.10, 534)

Amy spoke of how frightened her youngest son was when her oldest son became angry at home. Her daughter became responsible for containing her younger brother's fear and anxiety. "..it was really frightening" suggests that not only were the children scared in their family home, but so was Amy. It sounds as if her son's angry outbursts were unpredictable and uncontrollable, and Amy may have been frightened for her other children's safety and fearful of the extent

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to which she felt unable to constrain her son's behaviour. Keeping herself and her children safe was of paramount importance, and it seems that Amy's son's behaviour was such that he instilled fear in those around him.

"..there's been times when literally the last couple of holidays that (my son) was home, if he started to get angry, (my other children) would literally just disappear upstairs into (name of child's) bedroom and they'd both shut the door and she'd be like trying to keep him calm, it was really frightening…" (p.10, 485)

Emily, like Sophie, spoke of how her son can become angry over seemingly nothing, and likened living with her son to "living with a time bomb".

"..he gets angry over nothing, the smallest thing goes wrong he just loses it, totally loses it. It's like living with a time bomb, it's really hard to live with someone like that" (p.9, 418)

The strong use of language in the words "time bomb" reflect the extent of her son's anger that could erupt at any time. It may also reflect her own fear of being unable to control the "explosion" which is her son. The knowledge that her son will have an angry outburst, together with the uncertainty of when this may happen, may leave Emily feeling in a constant state of tension and stress. There is a sense of fear that these mothers experience in living with the unpredictability of their children's behaviour, fearing when the next outburst may occur, fearing that they may say something to cause an unwanted outburst and fear of their child's behaviour when it happens. The mothers will do everything possible to prevent their child becoming overtly anxious, but not knowing what might trigger an outburst results in these mothers feeling anxious and tense.

3.4 OVERWHELMING SENSE OF TENSIONS

This theme includes the sub themes the mothers' self-blame, their desire for harmony within relationships in the home, their desire for their child to be accepted by others and their feelings of uncertainty about what the future may bring for their child. Underlying these themes seems to be the overwhelming sense of tensions that the mothers experience in parenting their child with autism and anxiety, in their roles as "mediator" within the home, and "protector" outside of the home.

3.4.1 Self-blame

The mothers spoke of the ways in which they felt blamed and judged when their child exhibited challenging behaviour in public. Underlying this seems to be the mothers desire for their child to feel accepted by society, and for them not to be perceived as bad parents because of others lack of understanding and ignorance.

Sophie worried that others may judge her negatively as a mother when her son is having a tantrum particularly because her son looks "normal". *"you get people like shaking their heads.. or umm tutting.." (p.20, 1062)* suggests that she feels blamed and that her son's behaviour is a reflection of her parenting ability. I wonder to what extent her fear of what others might think influences her beliefs about her parenting abilities and to what extent this increases the stress and anxiety that she may experience. Her beliefs about how she should or would like to manage her child's behaviour may be compromised with the way in which she is actually able to manage her child's challenging behaviour. Feeling judged and blamed by others may cause Sophie to feel increasingly stressed and anxious, and perhaps to doubt her own competency as a mother.

"..I've been out with him before when he's gone off on one, screaming and shouting and it's not pleasant…...I find that difficult as well because he looks normal…[…]..you get like people shaking their heads or umm…you know tutting.." (p.20, 1061)

Ellie felt that she should have been able to manage her son's ongoing tantrums when he was little and despite trying everything the tantrums would go on for long periods of time.

"..with terrible tantrums and that sort of thing that we just couldn't believe that we couldn't manage them.[..]..And everyone would advise you're not being consistent enough, you're not doing this..we …we are…" (p.1, 19)

In saying *"everyone would advise you're not.."* suggests that Ellie felt criticised by others and needed to justify that she was doing everything others had advised. It perhaps suggests that she felt her son's tantrums were reflective of her parenting and that she should have been able to find a way in which to control and manage her son's behaviour. *"We are",* sounds like Ellie is defending herself against other's criticism, and that she felt blamed for her child's tantrums and challenging behaviour.

Charlotte spoke of how she used to be embarrassed when her son had a tantrum in public, but that over time she stopped caring about what people thought. "Embarrassed" suggests Charlotte felt ashamed by her son's behaviour and self conscious in front of others, perhaps believing that others were forming negative judgements of her parenting ability.

"initially when he had these outbursts it was very embarrassing..[..]..everyone was watching, and [..] and then I don't know if it just happened just through time just like urgh I don't care what anyone thinks, I don't care if the whole restaurant is looking, I don't care if the whole of the year of parents is watching me, I'm over it now" (p.7, 342)

This perhaps suggests that through developing an inner confidence of herself as a mother, or by developing an acceptance of her son's behaviour and being able to separate herself from her son's behaviour, Charlotte was able to develop a protective barrier protecting herself from the outside world.

Amy spoke of learning to accept the way in which others might judge her son and her desire to protect him from this. In contrast to the other mothers, Amy does not seem to experience feeling blame or embarrassment for her son's behaviour, but instead feels irritated by their reactions. Her annoyance is directed outwards towards other's reactions as opposed to directing it inwards towards herself.

"..you know coming to terms with the fact that there's such ridiculously ignorant people out in society and…wanting to protect him you know..[…]…I don't feel embarrassed. I feel frustrated by other people. I feel intensely proud of him..[..].." (p.16, 769)

3.4.2 Desire for acceptance

The mothers' desires for their child to form friendships contrasted at times with their child's social motivation and perhaps was symbolic of their need for their child to be accepted amongst their peers. Their child's ability to form friendships perhaps implied that their child was liked and viewed positively by others, and in

these instances they spoke of their gratefulness that their child had been accepted by others and formed these relationships.

Some of the mothers' desires for their child to form friendships contrasted with their child's apparent lack of social motivation. Perhaps this links with their worries about how their sons will manage and live independently in the future. Being able to form relationships with others may play a role in how these mothers imagine their child's future life to be and a life without friends may be perceived as lonely and isolating. This may contrast with the child's current wishes of feeling no need for friendships with others. The mothers questioned themselves as to what might be best for their child socially, torn between their understanding of their child's anxiety in developing friendships and their fear of their child becoming increasingly isolated.

".. …how we can help him socially even though he says "I don't need to be friends with any of those other people", you know.. "I'm happy as I am", but you know, I'm not convinced about that.." (Sophie, p.9, 482)

"why would you think I'd want to go there?"…so I suppose I kind of think I don't know…(p.11, 512)..[…]…but he then isolates himself…..(Anna, p.11, 523)

Ellie described her son as "a funny boy" and spoke of him having a few friends who he hangs around with.

".. He's a funny boy, he's got a really good sense of humour, a bit wacky….and now he's found his niche with these two other boys..they laugh hysterically together as well which is fantastic.." (p.7, 512)

The words *"which is fantastic"* speaks of the relief and the pleasure that Ellie feels in her son being part of a small friendship group in which he is able to laugh and be himself.

Ellie spoke of her frustration with the way in which her son's autism was not understood by some and how others made judgements about her son with regards to his label of autism. Ellie went on to explain that her son is not "typical" and that you need to get to know him. The need for others to see her son as an individual and not make judgements about him based on his label of autism is evident here. Underlying this may be her desire for others to accept her son for who he is, and not make judgements about him based on their stereotyped understanding of what it means to have autism.

"so that's the thing you grapple with…because they do a little bit of reading and they say oh yes, he's bound to have problems with this…[..]..And you think he's not like that…you've got to get to know him….you can't assume all these things are going to apply to him…" (p.10, 440)

Emily, too, spoke of how grateful and appreciative both she and her son are that he has a friend who understands him.

"..I was just so grateful that he's got a friend like that that really gets him.[..]..if somebody understands (my son) it means the world to him..." (p.6, 267)

A mother's need for her child to have a friend who he can relate to seems to be desperately important and for her child to feel understood by another, equally so. This need for acceptance, for their son to be liked by others may reduce the burden of responsibility that the mother feels for their child. The need for their

child to become more independent may also represent their desire for the parent child relationship to develop in the way that neuro-typical parent-child relationships may develop, with children being able to become increasingly independent as they become older and separate themselves from their parents. Emily describes how others speak of her son so positively, and her pride and love for her child is so clear in the way she speaks about him and describes him. This quote suggests how important it is to Emily that her son is viewed and described positively by others.

"everywhere I take him, all my family and all my friends are just ..think he's the most wonderful child you know he really touches them..because he is, he is a really polite, just a really thoughtful, lovely child.." (p.8, 391)

Similarly, Grace spoke of her son not realising he was "different" to the other children, as there was a small group of children with similar special needs to her son and he has been able to develop a close relationship with another child.

"..I think it's helped because there have been other children that are similar to him..especially his relationship to (friend) who also has learning..has a language disorder.." (p.10, 462)

Grace later spoke of how she feared that her son's flapping would be viewed negatively by others. Her desire that he be seen as "normal" suggests the extent to which she perhaps desired him to be accepted by others and not to be judged as being different.

" it might seem a bit cruel to almost stop them doing, but I felt it was making him look different..[..]..because kids can make judgements… we all make judgements about people very quickly don't we.." (p.18, 903)

Amy expressed her belief that her son would have felt sad had he been aware of not developing friendships, and this perhaps speaks of the mothers expectations and desires for their children to form friendships and the anxiety experienced by both when this does not happen. Amy has no expectations of her son being able to develop relationships with others and therefore has no anxiety about this. Her relief in knowing that her son has no need for friends suggests that perhaps the mothers feel anxiety when their expectations and desires are not met.

"I genuinely feel grateful that I don't have to experience (my son) feeling sad that he doesn't have friends. Friends are not part of his life". (p.14, 714)

Charlotte explained how her son doesn't desire friendships but that he has close family relationships and seems content with this. She suggests that neither her son or her have any expectations about her son socialising and that her son has perhaps not yet reached the stage in his development in which he desires to be part of a social group. Charlotte seems to accept her son's developmental stage and that he currently has no need for friends. It seems that they wouldn't necessarily add anything to his life. She seems to be content that her son has formed other close relationships with family members and therefore perhaps does not perceive him to be alone in a way that he might be if he was not part of a close family network.

*"..so it's not that he's not got anyone or that he's lonely but he doesn't have that
sort of need to you know or he hasn't got to the stage that he wants to go out
and socialize. He's very close to.. he plays with his brother a lot..he's close to
his grandparents.." (p.8, 396)*

The mothers seem to desire for others to accept their child regardless of the
label of autism. Underlying their desire for their child to develop friendships may
be their need for their child to be accepted by others. Friendships would enable
their child to become more independent, giving them more autonomy and
decreasing their dependence on their parents.

3.4.3 Desire for harmony within the home
Some mothers' spoke of the conflict between their husbands and their children
and their role as mediator within the home. In experiencing the tension, their
desire for harmony and peace is evident as they become torn between the two
parties, "pulling them apart".

Anna described the conflict between her son and her husband and the strain
that this placed in the family home. The tension was such that Anna
experienced the weekdays as being calmer when she was solely responsible for
looking after her son. Anna perhaps felt a sense of relief and comfort when her
husband was away.

*" it's a huge strain and him and (my husband) really clash, they really clash
because they're quite similar […]...sometimes (my son) will hit (my husband)
and I'll just like, have to pull them apart...[…]…during the weeks things are a bit
calmer, and on the weekend it's all….it's a nightmare.." (p.13, 650)*

The repetition of the words "really clash, they really clash" speaks of the conflict between father and son and the role of the mother as mediator "pulling them apart". The words "pulling them apart" suggests the verbal or physical force needed to separate her son and husband, and that Anna takes on the role of peace keeper.

Similarly to Anna, Sophie also spoke of the way in which she tried to keep her husband calm when in conflict with their son. It seems that she too was responsible for trying to keep peace within the home, perhaps exacerbating her own feelings of stress and anxiety in the process of doing so. It seems that the burden of responsibility is on the mother to try to maintain peace and prevent the escalation of conflict between others in the home.

"..and (my husband) ..the kind of the you know..the man in him kicks in..and it was difficult for him to stay calm..[…]..he would get really angry and I would be trying to say (to husband), calm down.. calm down, whilst (my son) was at him and that was really difficult.." (p.13, 683)

Ellie too, spoke of wanting to keep the peace between her husband and son, preferring to avoid further conflict, experiencing the "fights" as "dreadful".

"..and I think oh my god, and they end up in a screaming match with me saying STOP…umm..yeah…so we we we ..argue about it..[..]..I'd rather try and avoid the fights because the fights….[…]..they did used to be dreadful.." (p.18,844)

It seems that Ellie felt exhausted from the constant strain of managing her son's behaviour and felt it necessary to parent in a less rigid way to reduce the tension

at home. The word "strength" suggests she no longer has the energy to keep fighting and has found a way in which to make their relationship more peaceful.

"I'm not sure we've got the strength to keep battling things over we don't have to battle over and it think that's probably how we've coped. I think probably we have decided to be less rigid ourselves…" (p.17, 804)

3.4.4 Uncertainty about the future

The mothers spoke of their fears as to how their child would manage and cope in the future. This is indicative of the ways in which they had to accept as a mother that their child's future was more uncertain than had their child been neuro-typical. These mothers spoke of their worries as to whether their child would be capable of living independently, and their underlying fear of how their child's life would be if this was not possible.

Anna's fear is that her son will be alone in the future and worried about who would care for him if she was not around. She spoke of how she felt solely responsible for her son, believing that no-one else understands him in the way in that she does and is suggestive of the huge responsibility that this may place on her. In believing that only she can truly relate to her son, she may be unable to share the responsibility of looking after him with anyone else. The image of her son being alone and isolated in the future perhaps mirrors her own feelings of isolation in caring for him on her own.

"..I think what's really hard is that there's no one else that can do it..(p.15, 734)...[…]….my worry with him is that he'll be on his own..and if I'm not around, I don't know who will look after him...." (p.18, 908)

For Sophie, accepting that the diagnosis was forever was the hardest thing for her. She spoke of it as being a "double edged sword", the diagnosis offered relief and provided her son understanding for why he was feeling the way he was but at the same time knowing that this condition would be forever.

"…and I think when you get a diagnosis of autism that is the hardest hardest thing that it's forever…..it's a double edged sword, partly relief because we kind of knew it was anyway and umm and know that we could explain to him why…" (p.17, 919)

In referring to the "hardest hardest thing that it's forever", Sophie speaks of the full extent to which autism will affect her son's life and her own life. This is something that is not going to go away and that her son together with the rest of the family will need to learn to deal with. It seems suggestive that the diagnosis is forever for both her and her son and the extent to which she feels she has also been given a life sentence of some kind. In knowing that the diagnosis is forever, Sophie is uncertain of what this will mean for son's future and the ways autism will impact on how he is able to live his life.

Sophie spoke of her current worries about her son's lack of attendance in lessons, his anxiety preventing him from being able to attend. Her worries about him not achieving his full potential academically lead her to worry about not knowing how her son would live independently in the future. Her anxiety about how he is able to function now, is exacerbated by her thoughts of his ability to live independently as an adult. The uncertainty of how her son will live his life is in stark contrast perhaps to the way in which a mother hopes and expects her child's future to be.

"…he could do anything he wanted..but he has to get to lessons…(p.17, 909).[..]..and then you think about..will he be able to live on his own..[..]..how will he cope with the …kind of stresses of everyday life and dealing with things.."
(p.17, 919)

Sophie went on to speak of how she will always feel worried and that her anxiety about her son will always be there.

"…I think I always will do with him..umm…because there's always something, there's always some aspect of his life that's not quite going the way it's supposed to. Nothing is ever ..umm…ever ..um even with him." (p.16, 860)

It seems that there is a knowing that her son is going to struggle in life, and that she will always worry about some aspect of his life. In saying "nothing is ever ..even with him" suggests that nothing ever goes smoothly for her son or perhaps as planned. There will always be challenges ahead in which her son will need support to manage and overcome.

Emily spoke of her inner struggle, wanting to give her son more independence but fearing that in doing so her son's vulnerability might mean that others could take advantage of his trusting nature. It sounds as if she needs to weigh the benefits of giving her son some independence against her fears of his vulnerability and what could happen. Her need to protect her son is evident.

"..I'm very worried about his future because he's vulnerable, he really is..[..] I would love to be able to give him independence eventually [..]..you know make his own way to school, not straight away …but I'm really worried about it because he's so vulnerable.." (p.2, 85)

Emily spoke of her worries regarding her son's mental health, and her fear of what will happen as her son becomes older. The knowledge of her son's current mental health perhaps instils a fear within Emily, and is suggestive of her underlying anxiety regarding how her son will manage in the future.

"…I'm very worried about him getting depressed as he's getting older..(p.10, 472) [..]..I've got lots of worries about his future is going to be.." (p.10, 497)

Emily uses the word "worried" repeatedly suggesting that her fear of what the future may bring is a constant source of anxiety for her. Emily also refers to her son's "vulnerability" suggesting that she feels he may be in danger being on his own in the outside world. It perhaps implies that her fear of threat is high, as she continues to balance her desire for his independence against her role as a mother to protect and keep her son safe.

Like the other mothers, Grace also spoke of her worries about her son's future, and how he would manage to live independently and make his way in the world.

"I worry about what the future holds for him, how is he going to be able to cope, what's he going to do as a job..?" (p.24, 1189)

Amy likened the shock of hearing that her son had autism to that of being in a car crash. The word "crash", suggests the extent to which Amy felt she had been physically and emotionally crushed, wrecking and changing her life in that moment. The diagnosis had been unexpected, and Amy's life had taken a turn that she had not foreseen. She spoke of her need to accept that her son's future was not going to be how she would have imagined it to be and the difficulties of accepting the loss of her dreams for her child.

"it was absolutely horrific (deep breath) and then we were driving home and the shock that I was feeling I would equate to having been in a car crash, quite a bad car crash because I just did not anticipate that at all.." (p.1, 141)

"..but it's as a parent, it's a gradual sort of, almost like a bereavement where you are grieving for the life that your child's not going to have.." (p.3, 109)

Amy suggests that she also had to come to terms with the different role she would now need to take on as a mother. She may have been grieving not only for the loss of the life that her son would not be able to have, but also for the loss of her role as a mother in the way that she would have expected. Underlying her anxiety may also be Amy's uncertainty about what the future may hold for her son, what he will be able to achieve and how the extent of his disability will impact upon the quality of his life.

3.5 SUMMARY

The analysis portrays the all-encompassing nature of the ways in which these mothers experience their autistic child's anxiety within their families. The conflict experienced both internally by the mothers in their desires to protect and do their best for their children is demonstrated by their questioning of to what extent they should push their child against their will and the perceived emotional cost of doing this. The conflict within the family home is played out through the tensions within relationships, and the unpredictable family life, likened to "living with a time bomb". The power balance between the child and mother seems to be tentatively balanced with the child perhaps inadvertently holding the power, leaving the mother feeling helpless and powerless when faced with the extent of their child's anxiety. The overwhelming need for others to be able to understand their child, and not make assumptions based on the label of autism is evident,

and their appreciation for other's understanding and knowing their child is clear to see. The relentlessness of living with their child's anxiety experienced by the mothers seems to mirror the constant anxiety experienced by their child. The knowledge that the diagnosis "is forever" and cannot be "fixed" by their mothers perhaps serves to cause further tension within the parent child relationship

Underlying each mother's account was the sheer resilience, determination to do the best for their child, and pride and love that each mother conveyed for their child. The relentlessness of looking after their child, and desire to help their child to manage their anxiety seemed limitless, with the mothers doing whatever they could to access appropriate help and provide a loving environment for their child. Their desire for their child to be understood and not labelled under the term "autistic", to be appreciated for their many talents and abilities, and to be accepted by others was evident throughout the interviews.

CHAPTER FOUR: DISCUSSION

4.1 INTRODUCTION

This study explores how mothers make sense of the experience of parenting their child with autism and anxiety in order to help inform and develop future treatment for anxiety in autistic children. The findings in this study speak of the all-encompassing ways in which these mothers experience their child's anxiety and autism within their families, and their deep love for their child expressed in their devotion to helping their child in every way possible.

This chapter consists of a brief summary of the study's findings followed by a section on the findings in relation to the empirical research, highlighting the new findings that my study adds to the current body of literature. The chapter goes on to discuss findings in relation to theory, and explores the theory of ambiguous loss, parental self-efficacy and systemic therapy, which serve to increase our understanding of the study's findings and suggests ways of working with families with autism in the future. The chapter concludes with implications for counselling psychologists, suggesting that counselling psychologists are well placed to work relationally with parents and their autistic children to help promote emotional well-being in families with autism.

4.2 BRIEF SUMMARY OF FINDINGS

The findings in my analysis have been divided into three super-ordinate themes: mothers' internal struggle, the mothers' loss of self and the overwhelming sense of tensions that the mother seems to experience in parenting her child with autism and anxiety. They described the ways in which the mothers experienced living with their child's anxiety as relentless, and all encompassing, and how the mothers adjusted their lives to help manage their child's anxiety.

4.2.1 Mothers' internal struggle

This theme describes the mother's internal dilemmas with regards as to how best to manage their child's anxiety. The question of how much to challenge their child at the cost of experiencing their child's physical and mental distress arose leaving the mother feeling in a constant state of inner angst. The mothers also seemed to feel overwhelmed in their desire to be able to "fix" the problem and perhaps experienced feelings of failure in their roles as mother in being unable to do so. This constant questioning of self suggests the extent to which the mothers may experience their child's distress, and are left constantly questioning themselves not knowing how best to help their child manage the anxiety. This constant angst may result in the mothers experiencing lower levels of parental self-efficacy, further undermining their confidence in their parenting abilities.

Within the theme of the mothers' internal struggle, mothers in this study also spoke of their struggle to access treatment for their child, and once having accessed it were faced with the difficulty of their child not being able to engage with the support on offer. The uncertainty in not knowing how to best manage their child's anxiety may have served to increase the mothers' own internal worries, their sense of desperation and subsequent feelings of isolation becoming apparent. Some of the mothers reported that even when their child was able to access help they were unable to engage. They believed that for the treatment to be useful their child needed regular reinforcement, and that the help on offer was not enough to improve their child's anxiety. This has important implications for the way in which treatment is developed for anxiety in autistic children, and what type of intervention might be most appropriate and useful given the child's presenting difficulties.

The mothers spoke of the relentlessness they experienced living with their child's anxiety, and how it seemed to use up all of their internal energy in the same way that it did for their child. The mothers spoke of how their day was endless, exhausting and unremitting, with one mother speaking of her desire to escape desperately needing a break. The provision of emotional support to their child felt constant and left the mothers feeling on edge and in a permanent state of anxiety and exhaustion.

4.2.2 Loss of self

This theme describes the ways in which the mothers adjusted their lives to meet their child's needs, and in doing so, seemed to experience a subsequent sense of loss of freedom and loss of self. Some described life as feeling like they were prisoners in their own home. In experiencing this loss of self, came also the sense of loss of power and helplessness, there being a role reversal in which the child was able to exert their influence and control over the parent. In living with unpredictability, life was described as "living with a time bomb", and the mothers described how they felt they had to control their own behaviour to try to prevent an outburst from their child.

4.2.3 Overwhelming sense of tensions

The final theme described how the mothers seemed to feel an overwhelming sense of tensions in caring for their child. Their desire for their child to be accepted by others was evident and their need for their child to be seen as an individual and not defined by the label of autism was also apparent. The mothers seemed to be torn, trying to keep the peace between different members of their family and strove for harmony within the family home. The mothers spoke of the blame they felt towards themselves, feeling that they were seen to be accountable for their child's outbursts in public and that their child's

behaviour was seen as a reflection of their parenting ability. Their uncertainty about their child's future left them feeling anxious and worried, not knowing how their child would be able to live independently in the future and who would be able to care for them if they were not around. Underlying the mothers' accounts is their utter devotion and love for their child and their desire to do everything to accommodate and adjust to their child's needs in order to help their child to manage their anxiety and autism.

4.3 FINDINGS IN RELATION TO EMPIRICAL RESEARCH

The body of literature on parental experiences of their child's autism supports my findings in several ways. Although there is little research on parental experiences focusing on their autistic child's anxiety, the research suggests that parents find caring for their autistic child exhausting and overwhelming. Studies describe the struggles mothers encounter in accessing appropriate help for their child and the challenges they experience in doing so (eg. Safe, Joosten & Molineaux, 2012). Research describes how the role of mothers was seen to be all encompassing, exceeding the demands that mothers of typically developing children may experience (Nicholas et al., 2106).

The literature spoke of the mothers' exhaustion in caring for their child, and their reports of extreme tiredness at the end of each day (eg. Nicholas et al., 2016; Gill & Liamputton, 2011). Nicholas et al., (2016) described the ways in which the mothers "lived and breathed ASD", it taking up every minute, every hour of their day. Similarly, Safe et al., (2012) suggest that much of these mothers work was cognitive unlike mothers of children with physical disability. This cognitive work was said to involve planning and preparation and may feed into the mother's exhaustion experienced in looking after their autistic child. The authors reported

that the mothers spoke of their constant exhaustion in managing the multiple

roles required to look after their autistic child, and their desire for a break.

The literature also referred to the mothers' experience of living with the

unpredictable nature of their child's autism. This sense of feeling on edge, was

also described in Woodgate, Ateah and Secco's study (2008) which described

how parents developed a heightened sense of vigilance feeling that they were

"walking on egg shells" (p.1079). The unpredictable nature of ASD regularly

impeded expectation and daily routine (Nicholas et al., 2016). Studies also

spoke of the mothers desire for their child to be socially accepted, included and

their desire for their child to lead a fulfilling, happy and independent life (Safe et

al., 2012).

 "Uncertainty around the child's future" seems to be a common finding supported

in the literature. For example, in Nicholas et al.'s study (2016) mothers spoke of

living with both short and long term uncertainty, not knowing the extent to which

their child would be able to function independently as an adult. Mothers worried

about their child's future, and often expressed concern with regard to how their

children would manage if they were no longer able to look after them.

The literature describes how mothers felt judged by others when out in public,

leading them to blame themselves for their child's behaviour. Parents spoke of

the criticism they received, and felt that this was more common for parents of

autistic children, the disorder not being physically apparent to others (DePape &

Lindsay, 2015). Some studies suggest that parents of autistic children

experience more stigma than families of children with other disabilities such as

Down syndrome (Olsson & Hwang, 2001). Gill and Liamputtong (2011) spoke of

how the physically normal appearance of the autistic child meant that parents

may experience increased negative reactions from the public, with other studies indicating that parents of autistic children feel more anxious, and more stigmatised by the public (Olsson & Hwang, 2011).

Parents have described feelings of rejection and shame, and felt criticised for their parenting abilities (Gray, 2002b). Gill and Liamputton (2011) reported that mothers felt blamed by society for their child's inappropriate behaviour and that as a result they perceived themselves to be bad mothers. The mothers felt that the way in which they parented was thought to be responsible for their child's behaviour, which lead the mothers to blame themselves. These authors reported that mothers of children with ASD compared themselves unfavourably to other mothers, believing themselves to be inadequate and unsuccessful in their role as mothers.

Robinson, York, Rothenberg & Bissell (2015) highlight the ways in which blame undermined parents' confidence in their parenting abilities. Experiences of blame included self-blame together with parents blaming one another and feelings of blame from outsiders. Studies suggest that blame undermined parents' confidence in their parenting abilities (Neely-Barnes, Hall, Roberts & Graff, 2011) and negatively impacted on the ways in which parents felt able to cope when faced with challenging situations (Kuhn & Carter 2006). As a result of the stigma parents felt and their feelings of self-blame, parents isolated themselves from their own extended family members and from the wider community (Gill & Liamputtong 2011).

McKeever & Miller (2004, p.660) describes how "the measure of a mother is her child" referring to the way in which a mother may feel that her mothering abilities are defined by the way in which her child behaves. These authors suggest that

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when a child "is not seen to measure well" – and is perceived to be badly behaved, the mother is equally seen to not "measure well" in her role as a mother. The mothers, similarly in my study, spoke of the ways in which they felt judged by others and blamed when their child exhibited challenging behaviour in public. The mothers perhaps felt that their child's behaviour was a reflection of their parenting abilities and felt that they should have been able to control and manage their child's behaviour.

The impact of caring for an autistic child on parents' lives is evident in the literature (DePape & Lindsay, 2015). These authors spoke of the overwhelming demands placed on parents of autistic children, their apprehension felt knowing and waiting for the next outburst to occur, and the difficulties experienced managing their child's challenging behaviour. DePape & Lindsay (2015) described in their study the way in which parents felt stressed and exhausted from caring for their child, some feeling overwhelmed, believing that things would not change in the future. Some parents described wanting to escape their family situation, and others believed their parenting abilities to be inadequate. Similarly, in this study, mothers spoke of their exhaustion and the relentlessness of living with their child's anxiety. They described how they experienced their child's anxiety as all encompassing, and the unpredictable nature of their child's behaviour.

Safe et al., (2012) noted how parents spoke of the overwhelming sense of responsibility that came with looking after their autistic child. Mothers spoke of their difficulties managing their child's behaviour and the ways in which caring for their autistic child imposed restrictions on their own lives which they felt impacted on their general well-being. Motherhood was described as having "extraordinary heightened maternal responsibility" when caring for a child with

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ASD, likening motherhood to full time caregiving regardless what the cost of doing this was for the mother (Nicholas et al., 2016, p. 931). Cashin (2004) described how parents experienced a loss of self in caring for their child with autism and felt pulled into their child's world. Similarly, in this study, mothers spoke of the ways in which they adjusted their lives to accommodate their child's needs and the subsequent sense of loss that they experienced in doing so.

4.3.1 Additional findings to the body of literature

My findings point to the emotional stress, anxiety and exhaustion that these mothers experience in caring for their autistic child particularly in relation to caring for their child's anxiety. In focusing on exploring the mothers' sense of their child's anxiety, my findings highlight the inner turmoil the mothers experience in trying to help manage their child's anxiety, and their constant internal questioning of themselves in how best to do this. Their sense of desperation, helplessness and powerlessness becomes apparent in the face of their child's extreme anxiety and the subsequent ways in which they felt they had to adapt and adjust their family's lives to accommodate their child's needs. This inner angst and inner turmoil does not seem to have been explored in the literature, and I wonder to what extent these mothers constant internal questioning, feelings of powerlessness and feelings of loss of self may undermine their parental self-efficacy. Parental self-efficacy refers to parents' beliefs regarding their capability in parenting their child (Giallo et al., 2013) and will be explored later on in this chapter.

The balance of power between the mother and child in which at times, the child is able to exert their influence and control over the mother, is another area that has not been explored in the current body of literature. The sense of loss of self experienced by the mother is perhaps further exacerbated by the gap between

her expectations of motherhood and the reality of the way in which she is able to parent her autistic child. The self-blame that some of the mothers experience, believing their child's behaviour to be reflective of their parenting abilities perhaps serves to further undermine their self confidence and self-esteem. The theme of control and power within families with autism has not been explored in the literature, and increasing our understanding of mothers' sense of agency and its association with parental stress and anxiety may provide insight into how best to help families with autism reduce conflict within the home.

4.4 FINDINGS IN RELATION TO THEORY

4.4.1 Theory of ambiguous loss

O'Brien (2007) suggests that the theory of ambiguous loss may help parents of autistic children to become aware that the distress they may be experiencing could be as a result of the ambiguity of their situation rather than being inherent to them. This may result in increasing their insight and understanding of their situation and perhaps have implications with regards to reducing self-blame and in the longer term increasing parental self-efficacy and self-esteem.

The theory of ambiguous loss (Boss, 1999, 2006) suggests that stress occurs within a family as a result of change, the most severe stress resulting from change that is considered to be ambiguous and unclear. The ambiguity of the situation means that the outcome is uncertain and there is no clear resolution to the situation. O'Brien (2007) suggests that parents of children with ASD may experience ambiguous loss, as they learn to accept that the child they have is different to the child they expected they would have. Furthermore, parents of autistic children need to learn to manage and navigate the ambiguity of their child's autism and subsequent changes in the roles of family members, all of which adds to parental distress.

Parents of children with autism are particularly susceptible to experiencing a sense of ambiguous loss as a result of the ambiguity of their situation. Areas of ambiguity likely to contribute to parental stress include lack of clarity in the diagnosis, the uncertainty of outcome, the daily change in the child's apparent ability to function, the normal physical appearance of their child which may serve to raise expectations and hope for the child's ability to function within the family, and the fear that relationships will be affected by the autism (O'Brien, 2007).

Identity ambiguity (O'Brien, 2007) is said to occur when the boundaries between the child and the parent become enmeshed, with the parents of an autistic child finding it difficult to separate themselves from that of their child. This can be a common occurrence in families with autism, as parents report the highly intense and excessive caregiving demands exceeding those of parents of typically developing children. In taking on the extra responsibilities and care needed to care for their autistic child, the parent may feel unable to separate their own life from that of their child's disability, and O'Brien (2007) describes this as "identity ambiguity" (p.137). Boss (1999) has associated the concept of identity ambiguity with resulting in feelings of being overwhelmed, and difficulty adapting to the changes that autism may bring to family life. O'Brien (2007) suggests that a mother may be thought to experience identity ambiguity when she feels that her own life is entwined with her autistic child's to such an extent that she may believe she is responsible for her child's autism and should be able to resolve the outcome for her child. O'Brien (2007) reported in her study that mothers with high identity ambiguity reported greater symptoms of depression and stress in relation to their child with ASD than those who were considered not to have identity ambiguity and who did not identify with their child's autism to the same extent. In cases of ambiguous loss, O'Brien (2007) suggests that parents may

learn to accept their child's autism but that they never fully let go of their image of what their child would have been like before being diagnosed.

The concept of ambiguous identity seemed to fit with the ways in which the mothers described the overwhelming relentlessness they experienced in living with their child's autism and the ways in which their lives were subsequently affected by their child's autism. The mothers expressed their desire to be able to "fix" their child's anxiety, and felt helpless and powerless in not knowing how to best help their child. The ambiguity of not knowing what treatment may best help their child was evident, and may have served to further exacerbate their stress and anxiety in knowing how to best manage their child's behaviour and how to best help them. Underlying some of the mothers' accounts also seemed to be the difficulty in separating themselves from their child, as they were overwhelmed in helping their child to mange the anxiety, and subsequently may have become enmeshed with their child's identity of autism. The impact of living with their child's anxiety and autism was extreme for some mothers, as in trying to alleviate their child's distress, they felt "imprisoned" perhaps reflecting the ways in which the child was also imprisoned by their anxiety and autism. Some mothers also spoke of their expectations of motherhood and how they had to come to terms with their child's diagnosis and what that meant for themselves and their child. Perhaps through working with clinicians to understand the theory of ambiguous loss and identity ambiguity, mothers may begin to be able to blame themselves less for their child's behaviour and begin to be able to separate themselves from their child's autism. In doing so, mothers may be able to begin to learn new coping strategies to help their families adjust to living with autism, perhaps helping them to feel less helpless and more empowered in their lives.

In their research on mothers of children with ADHD, McKeever & Miller (2004) suggested that these women experience their child's disability as their own. In their study exploring the experiences of women who mother children with ADHD, Carpenter and Austin (2007) described how these mothers reported feeling unable to speak about how they really felt for fear of how they could be judged. The authors noted that the mothers spoke of how they did not receive any positive feedback regarding their mothering skills from either outsiders or from their children's behaviour. This lack of positive feedback may have fed into the mother's low parental self-efficacy serving to reinforce her beliefs about her parenting skills and capabilities.

Arendell (2000) described how motherhood can provide women with a sense of meaning in their lives. At the same time however, this author discussed the "paradox" of motherhood in which women may feel a loss of identity and experience motherhood as both emotionally and physically demanding. Societal pressure suggests that mothers should feel content and happy in their roles, perhaps leading mothers to find it difficult to express any negative feelings about motherhood for fear their feelings may be viewed negatively by others. Maushart (1997) described this paradoxical nature of motherhood as being "the mask of motherhood" (p.21) in which mothers feel unable to express their true feelings and hide behind a "mask" when out in public.

The same may be true for the mothers in this study. This study's findings suggest that the mothers experience exhaustion and an unremitting relentlessness of living with their child's anxiety. These mothers do not, however speak of any negativity regarding their roles as mothers and I wonder to what extent they feel able to do so. The mothers spoke openly of their inner turmoil, their struggles, their desires for their child to be accepted by others and the

ways in which they had adjusted their lives to manage their child's anxiety. For some mothers, their lives had been changed irrevocably in becoming a mother, describing life "as feeling like I was under house arrest", "living with domestic violence", and "a constant feeling of worry and sadness". Yet, in all of these mothers' descriptions, there is no mention of feeling resentful or regretful towards their child and it may be that mothers did not feel this way, or it may be that as Carpenter and Austin (2007) suggest, the mothers felt unable to voice feelings such as these out loud. In perhaps wearing "the mask of motherhood", I wonder to what extent this contributes to the mothers stress and anxiety, in her attempts to live up to society's expectations of her as a mother. In believing that she may not be living up to the ideal image of motherhood, mothers' parental self-efficacy may be further diminished.

4.4.2 Parental self-efficacy

Parental self-efficacy is described as being the extent to which parents view themselves as capable and successful in their parenting role (Giallo et al., 2013). According to Bandura's (1989) theory, self-efficacy beliefs are formed by our experiences of success and failure, the extent to which a task is perceived as being difficult, interactions with others, and our emotional and physiological well-being (Giallo et al., 2013).

Studies of parental self-efficacy in parents of autistic children have shown an association between parental stress and depression and PSE (Kuhn & Carter, 2006). In their review, Karst and Van Hecke (2012) suggest that parental self-efficacy may be detrimentally affected in parents of autistic children, their confidence becoming undermined as a result of their difficulties in being able to help their child and as a result of being uncertain of the optimum treatment and intervention for their child. Kuhn and Carter (2006) examined the association

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between maternal self-efficacy and parental cognitions and found that maternal feelings of depression, stress and guilt were linked with self-efficacy. Mothers with higher levels of self-efficacy were found to be more active in their development of their children, suggesting that self-efficacy may also impact on parenting behaviours. Hastings and Brown (2002) reported that self-efficacy mediated the relationship between mothers' anxiety and depression and child behavioural problems, with mothers of autistic children reporting increased parental stress and decreased feelings of parental competence.

Studies suggest that fatigue may also affect parental self-efficacy and well-being in mothers of children with ASD (eg Giallo et al., 2013). These authors suggest that when parents of children with ASD are exhausted, it may become more difficult to use personal resources to parent the challenging demands of their autistic child. Thus, parents' perceptions of their ability to parent effectively may become undermined, leaving them feeling increasingly incompetent and dissatisfied in their parenting role. In the wider parenting literature PSE has been associated with parents use of positive parenting strategies, and their ability to manage challenging parenting situations (Coleman & Karraker, 1998).

The mother's sense of agency has also been associated with parental self-efficacy. Kuhn and Carter (2006) described this as the mother's active role in engaging with her child and her ability to identify strategies for her child, together with her ability to persevere in the use of these strategies for her child. Kuhn and Carter (2006) identified that a decreased sense of agency was linked with parental perceptions of self-efficacy. Studies have shown parental empowerment to be associated with positive outcomes in families of children with and without developmental disabilities (Nachshen & Minnes, 2005). Research suggests that loss of empowerment is associated with higher levels of

distress in mothers (Scheel and Rieckmann 1998) with families reporting high levels of empowerment more likely to report lower levels of distress.

Research on parental self-efficacy suggests that parents of children with autism may experience low levels of parental self-efficacy, resulting from their confidence being undermined in their ability to help their child manage their difficulties. This seems to be particularly relevant for mothers of anxious autistic children, the mothers in this study reporting their extreme exhaustion and the relentlessness of living with their child's anxiety. The mothers seemed to experience a loss of empowerment in their relationship with their child, and in not being able to "fix" their child's anxiety may have experienced feelings of loss of agency, and loss of hope in not being able to improve the situation. Exacerbating the mothers' low parental self-efficacy may be the difficulty in not knowing what the optimal treatment for their child might be. This is particularly relevant to the ways in which anxiety in autistic children may be treated, it not being clear at present the best way to help autistic children to manage their anxiety.

Research also suggests that mothers of autistic children experience higher levels of stress and anxiety than fathers in the same family (eg Hastings et al.,, 2005). In their study on parental self-efficacy and positive contributions regarding autism, Garcia-Lopez, Sarria and Pozo (2016) report that mothers experience significantly more stress than fathers, with fathers' levels of anxiety being influenced by the mothers' levels of parental self-efficacy. Fathers' positive perceptions of family cohesiveness decreased mothers' anxiety levels and improved their emotional well-being. These authors highlight the need to consider the impact of family dynamics and interrelationships on family adaptability when examining the outcome of families with children with autism.

In their studies on the interrelationships between mothers and fathers of autistic children, Hastings (2003) reported that the mothers' levels of stress were predictive of fathers' levels of anxiety and depression and child behavioural problems. In a later study, Hastings et al., (2005) reported that mothers' anxiety was positively related to their child's behavioural problems and partner's depression. Mothers' depression was found to positively predict their partners' depression, which was not found to be associated with the child's characteristics. This research highlights the importance of considering a systemic approach to working with families of autistic children, in order to explore and understand the family dynamics and interrelationships which may be impacting and influencing one another.

4.4.3 Systemic therapy

Much research into parental mental well-being has focused on the child as being the source of stress, studies finding that child behavioural problems may predict the level of stress and anxiety a mother of an autistic child may experience (eg. Hastings & Brown, 2002; Peters-Scheffer, Didden & Korzilius, 2012). Research such as Hastings et al., (2005) suggests the need to move away from focussing on the autistic child as the main predictor of parental stress, and encourages us to explore the family as a whole in relation to working with families with autism.

Systemic practice views problems within families as being relational rather than caused by one family member, believing that each family member brings different influences and ways of being into the family unit (Dallos & Draper, 2010). Systemic therapists focus on exploring the interrelationships between family members, and the ways in which the processes of adaptation may occur within families. Family relationships are seen to be an important factor in influencing the emotional well-being of family members (Dallos & Draper, 2010).

The literature is now moving towards exploring multi-dimensional models that focus on examining the process of family adjustment as influenced by the characteristics of the child together with those of the family (Hastings et al., 2005). The double ABCX matrix is one such model that has explored the ways in which parents adapt in families in which there is an autistic child. This model suggests that parental stress, marital difficulties, or poor emotional well-being may result from a number of factors including the parents' perception of the situation, their coping styles, and the familys' resources.

Similarly, Belsky's model (1984) suggests that parental well-being is influenced by the parents' individual characteristics, the child's characteristics, and environmental influences which subsequently impacts on a parents' ability to effectively parent (Derguy, M'Bailara, Michel, Roux & Bouvard, 2016). Using this model, Derguy et al., (2016) reported that parental stress was associated with the characteristics of the child together with the environmental resources available to parents, in particular the parent-grandparent relationship and the level of emotion expressed to the child. Derguy et al., (2016) highlight the importance of the parent-grandparent relationship in providing support to parents and reducing parental stress. The authors suggest that there has been little research into the association between parental stress and the parent-grandparent relationship, yet grandparents are noted as important providers of both emotional and respite support for parents of children with disabilities (eg Katz & Kessel, 2002). The authors also suggest the need for further research into the parents expressed emotion to their autistic children, their results indicating that high levels of expressed emotion were associated with high levels of parental stress. The levels of emotion felt about their child with ASD and the extent to which emotions such as anger, stress, anxiety are expressed to the

child may feed into the bi-directional nature of anxiety between parent and child and may exacerbate the situation.

Research suggests that parenting may influence their child's autistic related behaviour despite the aetiology of autism being neuro-developmental in nature (Baker et al., 2011). With this in mind, Baker et al., (2011) explored the longitudinal effects of adaptability on behaviour problems and maternal depression in families of adolescents with autism. Family level adaptability was described as being the extent to which the family system was able to change to meet the demands of the situational stress. This was seen to be reflected in the ways in which families were able to problem solve, compromise, be flexible and reorganise roles and responsibilities within the family unit. Baker et al.'s (2011) findings suggest that autistic children respond to their family environment, with family adaptability being predictive of changes in child behavioural problems that were not associated with the severity of the child's disability. The level in which the family is able to adapt was also found to decrease maternal depression that was independent of the child's behavioural problems and the parent-child relationship. These authors suggest that in families which maintain rigid processes and lower levels of adaptability, there is likely to be increased negativity amongst family members, and that adaptability and flexibility within families is likely to promote greater psychological well-being.

Structural family therapy is one of the initial approaches used in family therapy. An underlying assumption of structural family therapy is that the family system has become maladaptive as a result of its difficulty in adapting to a change in family circumstances that results in family members needs not being met. This approach describes two types of maladaptive family structure – family disengagement and family enmeshment (Parker & Molteni, 2017). Disengaged

families are considered to be overly distant, lacking in close family relationships. Closeness amongst one another within the family is thought to result in feelings of anxiety. In contrast, relationships within enmeshed families are thought to be overtly involved and highly emotionally dependent on one another.

Research suggests that families with an autistic child may become increasingly socially isolated and lack support within its wider family affecting its ability to cope and adapt (Ludlow, Skelly, & Rohleder, 2011). When working with what are considered to be "disengaged families", families that are thought to be lacking in close family relationships, structural family therapists highlight the importance of including both fathers and grandparents in treatment. Grandparents are often found to reduce parental stress providing them with emotional and financial support together with respite care for the child (Katz & Kessel, 2002).

Families with autistic children may also, in contrast to "disengaged families", become "enmeshed" as a result of the intensive and ongoing demands that need to be met in looking after an autistic child. Research has highlighted that some parents of autistic children are uncomfortable with the excessive closeness needed to care for their child with ASD (Ludlow et al., 2012; Myers, Mackintosh & Goin-Kochel, 2009). Family therapists are able to work with families to help develop and clarify boundaries between different members in families with autism.

Other studies suggest that family centred models may be appropriate to use when working with families with autism. For example, the Family Life-Cycle Model highlights the need to be aware of the different challenges that parents may face at each developmental stage and how they may impact on parenting

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experiences (eg DePape & Lindsay, 2014). Studies suggest that factors such as family involvement and empowerment, the building of collaborative partnerships with parents, and family involvement in the making of decisions should be enhanced (eg. Meisels & Shonkoff, 2000; Case-Smith, 2004). Boshoff, Gibbs, Phillips, Wiles & Porter (2016) highlight the need for parents to find time to address their own needs and well being, as well as that of their family, stressing the need to focus on the entire family's well-being when providing intervention for families with autism.

The research on parental self-efficacy, systemic practice and autism highlights the need to consider the family as a whole when working with families with autism. The literature suggests that parental stress is not solely predicted by the child's behaviour and severity of the condition but also by factors such as the parent's characteristics, the interrelationships within the family and environmental factors. Studies that have explored interventions for anxiety in children with autism suggest some positive outcomes for the use of CBT, highlighting the benefits of parental involvement in treatment (eg Chalfant et al., 2007). Perhaps in using a systemic approach, together with specific individualised programmes for the child, the emotional well being of all family members together with those of the autistic child will be improved.

4.5 SUMMARY

This chapter has provided an overview of this study's findings together with support from the current literature on anxiety and autism in families with autism. The literature supports my findings in discussing the extent to which autism may impact on the lives of families, and the way in which parents may find caring for their autistic child all encompassing and overwhelming. Furthermore, studies describe the struggle to access appropriate treatment, the unpredictable nature

of living with autism, the uncertainty felt regarding the child's future and the stigmatisation felt by mothers of autistic children. Some research reported that mothers felt blamed for their child's behaviour and that it was felt to be a reflection of their parenting abilities. As a result, some mothers perceived themselves to be bad mothers, comparing themselves unfavourably with other mothers.

As discussed there are few qualitative studies of how mothers make sense of parenting a child with autism and anxiety. My study adds to the body of literature of mothers' experiences of caring for their autistic child with particular emphasis on the meaning they attached to the anxiety their child experienced. There is little mention in the current literature of the extent to which the mothers experience inner turmoil and angst in the face of their child's distress. Their loss of sense of self becomes apparent in their identification with their child's anxiety and in the ways in which they adapted their lives to try to alleviate their child's distress. Their internal struggle of believing that as the mother they should be able to "fix" their child is apparent and their feelings of helplessness and powerlessness evident in the way in which they adapt to living with their child's anxiety. The extent to which the mothers struggle, balancing their own needs with that of their child is clear and needs further exploration. The balance of power in the mother-child relationship, and the way in which the child exerts his control within the family, also leaves the mother feeling disempowered, perhaps undermining her confidence and beliefs about her ability to successfully parent.

In relation to the theory, these findings seem to suggest that these mothers are likely to experience feelings of low parental self-efficacy and self-esteem, believing themselves to be inadequate parents and that their child's challenging behaviour is somehow a result and reflection of their parenting. Studies of

parental self-efficacy in parents of autistic children suggest that low parental self-efficacy is associated with fatigue, parental stress and depression. Low parental self-efficacy has also been associated with a mother's decreased sense of empowerment, which in turn has been linked with higher levels of parenting stress and psychological distress. The findings in my research seem to suggest that the mothers may have experienced feelings of low parental self-efficacy and a decreased sense of empowerment that may have exacerbated their own feelings of anxiety and stress.

The theory of ambiguous loss suggests that through increasing a parents' understanding of the ambiguity of their situation in relation to autism, parents may become aware that the distress they may be experiencing is as a result of their situation rather than being inherent to them. This may provide parents with the ability to view their situation from an outsiders' perspective, and empower them to develop coping strategies to reduce their own stress and promote well-being. The concept of ambiguous identity offers insight into the ways in which parents may become enmeshed in their relationship with their child, the boundaries and roles becoming unclear as a result of the necessary excessive care provided by parents of autistic children.

Systemic therapy provides a framework in which families with autism could be helped. By moving away from focussing on the child as the sole stressor, and viewing the family as a whole and the way in which family dynamics and interrelationships may impact and influence one another parental stress may be decreased. Research suggests that the extent to which families are able to adapt and be flexible is likely to promote greater psychological well-being within the family. Through decreasing parental stress and promoting parents' psychological well-being, parents may increase their feelings of self-efficacy

becoming more empowered to use different coping strategies which may help to reduce their child's anxiety. Through greater insight into the family dynamics and the ways in which different family members relate and respond to one another, systemic therapy may provide appropriate intervention in managing the child's anxiety and autism.

4.6 PERSONAL REFLECTIONS

The findings from this study have lead me to reflect on the theme of motherhood and the expectations that women may place on themselves in perhaps trying to achieve their ideal image of motherhood. The expectation that as the mother, they should be able to "fix" their child's anxiety, together with the gap between how they might have imagined motherhood to be and the reality of their situation may have further contributed to mothers' stress and anxiety in caring for their child.

The self-blame these mothers felt, their feelings of helplessness and being overwhelmed in trying to manage their child's anxiety and the all encompassing relentlessness of living with their child's anxiety lead me to reflect on how this may become entwined in low parental self-efficacy and low self-esteem. The anxiety and stress that mothers experience in caring for their autistic child seems to be further exacerbated by the anxiety the child experiences leaving the mothers feeling exhausted, overwhelmed and distressed. I wondered at the extent to which these mothers believed they had to wear the "mask of motherhood" (Maushart, 1997, p. 21) believing that they would be seen to be bad mothers if they were not thought to be coping with the demands of looking after their child. How might this affect what help they could receive for themselves to relieve their own stress and anxiety, and how might this "mask" increase the loneliness and isolation they might feel in caring for their child? In

reflecting on this, I thought about the mothers that I have encountered in my work at CAMHS, and thought about how in focussing on the child's difficulties, the mothers' angst and emotional distress may have been left unnoticed and untreated.

As a mother, I felt very emotional listening to these mothers' stories and the extent to which their child's anxiety and autism impacted on their lives. The mothers' sadness and tears left me feeling distressed and upset for them, as I empathised with the extent to which their child's autism and anxiety has impacted on their lives. I felt an emotional connection with each mother, and felt only admiration for their resilience and determination to care for their child. I was aware of my own helplessness when listening to these mothers, and my own thoughts of what support could be provided to the mothers to better equip them to be able to manage their child's anxiety and autism. I felt very aware of my own feelings when interviewing the mothers and my own sense of desire to be able to help the mothers to resolve the situation, and to reduce their own and their child' distress. I related to their distress in the face of their child's distress and wondered what options were available to these mothers. I used therapy and supervision to discuss my feelings and emotions on these issues.

I was aware that as my participants had been recruited through word of mouth, some of the mothers may have known that I am also a mother. I wondered to what extent if at all, my own identity as a mother may have lead these women to fully discuss the nature of their experiences or in contrast, would they have felt more comfortable speaking to someone who was not a mother? Did speaking to me mean that they feared being judged in the same way that some felt negatively judged as a result of their child's behaviour? Were they wearing any kind of "mask" in our interviews together, or did they feel able to speak openly to

me? I hoped that I had been able to put the mothers at ease and that they had felt comfortable enough to speak openly about their experiences and what it meant to them.

I found writing the analysis section very challenging, in particular interpreting the transcripts. I felt that I was not conveying the essence of the mothers' experience and struggled to portray the richness of the data in my interpretations. I worried that my interpretations could be wrong in some way and I did not want to misrepresent the mothers' voices or misinterpret what they had said. I also struggled with my research question and spent much time focussing on clarifying my question and the purpose of my research. My initial drafts of the analysis focused too much on the child's experience rather than the mothers' experience and I found it challenging to interpret the mothers' experience of their child's experience. I also struggled to solely focus my interpretation on anxiety, anxiety and autism being intertwined. I did not, however, want my analysis to simply reflect the mothers' experiences of autism, I wanted the findings to reflect the mothers' experience of their autistic child's anxiety.

I also found it challenging to ensure that my own assumptions did not influence my interpretation of the mothers' experiences. For example, on reflecting on the mother's experience of her child's violence, my own assumptions had been that this was a result of underlying anxiety, the research suggesting that anxiety may cause behavioural problems. I became aware of this assumption when re-reading the analysis, and checked the questions that I had asked the mother, and how the discussion of her child's violence had emerged during the interview. Given that I had asked open-ended questions about her child's anxiety, and the mother had spoken about his violent behaviour, I reflected that

the mother believed anxiety to be underlying or related to her son's violent behaviour. In constantly questioning myself about my interpretations of the data and asking myself whether the interpretation was grounded in the data and reflective of the mother's experience, I endeavoured to bracket my own assumptions. I spent time reflecting on my own experiences of motherhood to try to ensure that my experiences and beliefs about motherhood were not influencing my interpretations of these mothers' experiences. To what extent this can be totally bracketed, I am not sure, as my experiences of motherhood have become an intrinsic part of my identity.

4.7 STRENGTHS AND LIMITATIONS

The findings from this study were supported by findings in the literature and also added new findings to the current body of research. The findings highlighted the emotional distress, anxiety and relentlessness that these mothers experienced in caring for their child with autism and anxiety. The use of IPA enabled in-depth insight into the experiences of these mothers and increased our understanding of how anxiety is experienced within families with autism through the eyes of the mother. In highlighting the mothers' emotional distress, clinicians may become more aware of the mothers needs when working with families with autism. Clinicians may choose to work integratively with families with autism, so that the whole needs of the family may be considered together with those of the child.

However, there are some limitations of the study that need to be explored. Although I tried to ensure that the sample of participants was as homogeneous as possible, and interviewed mothers of autistic boys aged between 10-16 years old, due to the nature of ASD the autism and anxiety experienced by their children was in fact very different. This is reflective of the variability within ASD, and shows how anxiety and autism may be experienced in differing levels of

severity by autistic children. Thus some of the mothers' experiences were quite different depending on the extent to which their child experienced anxiety and was able to communicate this to the mother. Some of the mothers also spoke of their child's anger and violence in relation to discussing their child's autism and anxiety, and my understanding of this was that the mothers may have sensed that anxiety may have been underlying the violence and angry outbursts. This is my interpretation of the mothers' interpretation of their child's behaviour and may be interpreted differently by other researchers or by the reader.

The sample of participants was small and although the current study provides a detailed insight into the mothers' experiences of their autistic child's anxiety, the transferability of the results is limited. The sample of mothers were all white British women, thus lacking in cultural diversity. The women were also all married, and thus their experiences may not be reflective of single mothers. I also recognise that only mothers have been interviewed for this study, and fathers, siblings and other members of the family may offer further insight into our understanding of a child's autism and anxiety.

4.8 FUTURE RESEARCH

Further research using IPA should include a more diverse sample of mothers of autistic children and should also explore fathers' and siblings' experiences of anxiety within families with autism to further our understanding of autism and anxiety within the family context. This knowledge and understanding would be invaluable for clinicians who choose to work systemically with families with autism. Studies could subsequently be undertaken to explore the efficacy of working systemically with families with autism to determine the extent to which emotional well-being is improved within the family. This could be explored using a mixed methods approach to gain an understanding of how families

experienced the process of therapy and the ways in which they felt therapy may have impacted on their emotional well being. Future qualitative research could be undertaken to explore mothers' sense of agency and parental self-efficacy in families with autism to further develop our understanding of the mother-child relationship and how this may affect parenting behaviours and the emotional well-being of both mother and child.

4.9 IMPLICATIONS FOR COUNSELLING PSYCHOLOGY

This study has provided detailed insight into the mothers' experiences of their child's autism and anxiety. The study has highlighted the ways in which the mothers experience their child's anxiety as exhausting and all consuming and shown the ways in which they have tried to adjust their lives and their family's lives to accommodate their child's needs. The study has highlighted the importance of understanding the mothers' stress and anxiety in looking after her child with autism and the need to not just focus on the child but to also take into consideration the mothers' needs together with the needs of her family. In working with a mother of an autistic child, the counselling psychologist is able to work relationally with both the mother, child and other family members to help the family understand the child's needs within the family system. This study highlights the ways in which autism impacts not just the individual but the whole family, the child's anxiety experienced as being relentless by the mother, in much the same way as it is experienced by the child. Counselling psychology is able to provide the mother with increased insight and understanding of her own stress and anxiety, and may offer a therapeutic space within which she and her child may work together to develop more effective ways of being within the family system.

Clinicians could work systemically with families with autism to enable all members of the family unit to be included in the process of therapy and to receive support for the ways in which autism in the family impacts upon them. Mothers in particular need emotional support, and this could be offered through either family therapy or individual counselling to provide the mother with help in managing her own emotional distress. Counselling psychologists could also work with mothers to help develop their sense of agency and control within the family, and to help families to develop and adapt alternative perspectives of understanding and managing their child's anxiety and autism. Training could be given to practitioners working with families with autism to highlight the unseen needs of mothers, the focus currently being on the treatment of the autistic child. In addition, mothers highlighted the difficulties their child had engaging in treatment and the need for regular reinforcement for the treatment to be effective. Further consideration of how best to engage the child, together with additional parental involvement in any treatment may help to further improve the efficacy of any intervention for anxiety in autistic children.

4.10 CONCLUSION

This study explored how mothers make sense of parenting a child with autism and anxiety. Using IPA, semi-structured interviews were carried out with seven mothers of children aged between 10-16 years with ASD. Findings from the study included themes of the mothers' struggle, the mothers' loss of self, and the mothers' overwhelming sense of tension experienced in caring for her child with autism and anxiety. Findings were supported by the body of literature on parental experiences of caring for their autistic child and described the extent to which parents adjusted their lives to accommodate their child's needs. In addition, my research served to highlight the extent of the mothers' inner turmoil and angst in struggling to manage their child's anxiety. The balance of power

within the mother-child relationship seemed to be tentatively balanced, with the child exerting his influence and control within the family, inadvertently leaving the mother feeling disempowered and helpless. These feelings of helplessness, powerlessness and loss of self, perhaps serving to contribute to feelings of low parental self-efficacy and self-esteem.

The findings from this study suggest the extent to which mothers experience inner turmoil and anxiety in caring for their autistic child and in trying to alleviate their child's anxiety. The findings suggest the extent to which mothers experience emotional distress and the ways in which they have adapted their lives to help manage their autistic child's anxiety. These mothers spoke of the difficulties of accessing treatment for their child, together with their child's difficulty in engaging in treatment when it was made available. There seems to have been little support available to these mothers to address their own emotional needs. Counselling psychologists are well placed to work relationally with families to help increase their understanding of anxiety and autism, and to develop coping strategies to increase psychological well-being. This study highlights the need to provide additional professional support to help to alleviate mothers' stress and anxiety in caring for their autistic child, and in doing so, to help promote well-being in families with autism.

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APPENDIX A: PARTICIPANT INFORMATION SHEET

![City University London logo]

Title of study: *Parent's experience of anxiety in the family of a child with Autistic Spectrum Disorder.*

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

What is the purpose of the study?

Anxiety has become a recognized problem for children and adolescents with autism spectrum disorder (ASD), impacting on the child's behaviour and psychological well-being. Mothers of children with ASD are likely to experience increased stress, depression and anxiety compared to mothers of children with learning disabilities or typically developing children. It has been suggested that parents experience the most stress when their children exhibit perceived problematic behaviour. The anxiety that a child with ASD experiences may cause their behaviour to become more problematic (such as an increase in tantrums) which in turn may result in the parent experiencing higher levels of stress.

Parents are increasingly being encouraged to participate in the treatment of their children and the parental role in treatment has been found to be beneficial in improving outcomes for children with ASD and anxiety. Research has indicated that high levels of parenting stress lower the outcomes of success in treatment.

There has been little research exploring the relationship between parental and child anxiety in children and adolescents with ASD and anxiety but studies have indicated that parental anxiety significantly decreases for parents of children who have responded to treatment. These studies indicate that a parent's anxiety reduces with the reduction of anxiety in their child and that the anxiety they experience may be related to the severity of their child's anxiety.

Aims
This study aims to explore parent's experiences of anxiety in order to inform the development of future treatment for anxiety in children with ASD.

This study will be undertaken as part of a Doctorate in Counselling psychology programme at City University.

Why have I been invited?
Parents of children with ASD will be invited to participate in this study. Six to eight participants will take part.

Do I have to take part?

Participation is voluntary and participants may withdraw at any stage, or avoid answering any questions that may be thought to be intrusive. This will not affect any future treatment of the participant if they choose to withdraw at any point.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?
- You will be asked to take part in an interview which will last between 60-90 minutes.
- The research will take place over a period of two years
- You will meet for the one interview, if need be you may be asked to attend a second interview although this is unlikely.
- The interview will be an informal process in which you will be asked to talk about your experiences. You do not need to discuss anything that you are uncomfortable discussing.
- A semi-structured interview will be used in which open ended questions will be asked to give you the opportunity to lead the discussion and focus on what's important to you
- The interview will take place in a room to be confirmed

What do I have to do?
You will be expected to participate in the interview, and discuss your experiences of being a parent to a child with ASD and anxiety.

What are the possible disadvantages and risks of taking part?
The possible disadvantages of taking part may be that you discuss personal information which you find upsetting or distressing. If you do feel distressed in the interview information will be provided to help you seek further support.

What are the possible benefits of taking part?
It can be very therapeutic to be given the opportunity to discuss how you experience looking after your child with ASD and to focus on how you perceive anxiety may have impacted on yourself and your family.

Your experiences will raise awareness of the experiences of parents of children with ASD and help to inform the development of future treatment programmes for anxiety in children with ASD.

What will happen when the research study stops?
Once the study has been completed all data will be destroyed.

Will my taking part in the study be kept confidential?
- The researcher and supervisor will have access to the information – the information will be anonymised in the study
- The interviews will be audio recorded, these will be kept confidential and destroyed after the study has been completed.
- Personal information will not be used once the study has been completed.

- The data will not be shared
- The interviews will be confidential unless there is any indication of reporting of violence, abuse, self-inflicted harm, harm to others, criminal activity
- The records will be stored at the researchers home and destroyed after use

What will happen to the results of the research study?
The results of the study will be incorporated into the thesis and anonymity will be maintained. If you would like to receive a copy of the summary of results you can contact me via email. If the research was to be published in a Psychology Journal, anonymity would be maintained and you are able to request a copy.

What will happen if I don't want to carry on with the study?
You are free to withdraw from the process at any time. There is no need to provide an explanation and there are no consequences for your withdrawal.

What if there is a problem?
If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: **Parent's experience of anxiety in the family of a child with Autistic Spectrum Disorder.**

You could also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: █████████████████████

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?
This study has been approved by City University London Research Ethics Committee, (Ethics approval code: PSYETH (P/L) 15/16 51).

Further information and contact details
You can contact Jo Rosenberg: █████████████████████████. *or my supervisor Professor Marina Gulina at* █████████████████████ *for any queries or further information.*

Thank you for taking the time to read this information sheet.

APPENDIX B: CONSENT FORM

CITY UNIVERSITY LONDON

Title of Study: **Parent's experiences of anxiety in the family of a child with**

Autistic Spectrum Disorder (ASD).

Ethics approval code: PSYETH (P/L) 15/16 51

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve : • being interviewed by the researcher • allowing the interview to be videotaped/audiotaped • making myself available for a further interview should that be required	
2.	This information will be held and processed for the following purpose(s): To explore parent's experiences of anxiety in order to inform the development of future treatment for anxiety in children with ASD. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

_____ _____ _____
Name of Participant   Signature   Date

Jo Rosenberg   _____
          _____
Name of Researcher   Signature   Date

When completed, 1 copy for participant; 1 copy for researcher file.
Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

APPENDIX C: INTERVIEW SCHEDULE

Research question: Parent's experience of anxiety in the family of a child with

Autistic Spectrum Disorder (ASD).

Aim: To explore parent's experiences of anxiety in order to inform the

development of future treatment for anxiety in children with ASD.

INTERVIEW QUESTIONS

Introductory questions

1. Tell me about your family and your child

Prompts:

When did you learn of your child's condition?

How did you feel at the time?

2. Tell me about where you are at now?

Prompts:

How old your child is, what school they attend, siblings, how your child's

condition affects life in general

3. What are the main issues that you are facing?

Your child's behaviour and feelings

1. How does your child behave in general?

2. Can you tell me about your child's feelings?

Prompts: would you describe your child as happy, anxious, angry, easy going

3. Can you tell me about any anxiety your child has?

Prompt: In what ways do you think your child demonstrates this anxiety in the way he behaves?

4. In what ways has your child's behaviour changed over time?

Prompt:

What do you perceive the reasons for the changes in behaviour to be?

Parent's stress and feelings

1. What are your perceptions of yourself as a parent?

2. Can you tell me about your own emotions in looking after your child?

Prompt:

Have you experienced periods of anxiety or depression in relation to looking after your child, and if so do you feel able to tell me about them?

How does this manifest itself in your own behaviour?

3. How do you manage your own well being?

Relationship with your child

1. Tell me about your relationship with your child?

Prompt:

Can you describe if and how your relationship with your child has changed over time?

2. In what ways do you think your own psychological well being may have impacted on your relationship with your child?

3. What if any, do you think the connection between your own feelings and well-being and your child's feelings and behaviour may be?

Treatment

1.Can you tell me about the help that you have received and how useful it has been?

Prompt:

What additional help would you have found or find useful?

2. Is there anything else you would like to tell me that I haven't asked?

PARENT'S EXPERIENCE OF ANXIETY IN THE FAMILY OF A CHILD WITH

AUTISTIC SPECTRUM DISORDER.

DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it's finished we'd like to tell you a bit more about it.

Anxiety has become a recognized problem for children and adolescents with autism spectrum disorder (ASD), impacting on the child's behaviour and psychological well-being. Mothers of children with ASD are likely to experience increased stress, depression and anxiety compared to mothers of children with learning disabilities or typically developing children. It has been suggested that parents experience the most stress when their children exhibit perceived problematic behaviour. The anxiety that a child with ASD experiences may cause their behaviour to become more problematic (such as an increase in tantrums) which in turn may result in the parent experiencing higher levels of stress.

Parents are increasingly being encouraged to participate in the treatment of their children and the parental role in treatment has been found to be beneficial in improving outcomes for children with ASD and anxiety. Research has indicated that high levels of parenting stress lower the outcomes of success in treatment.

Thus the parent's mental health plays a role in impacting on the success of the child's treatment and overall family functioning.

Recent literature has begun to examine the most effective intervention to treat anxiety in children with ASD. Cognitive behavioural therapy has shown some promising results but at the moment clinicians lack clear guidelines as to which would be the most effective interventions when working with children with ASD and anxiety.

There has been little research exploring the relationship between parental and child anxiety in children and adolescents with ASD and anxiety but studies have indicated that parental anxiety significantly decreases for parents of children who have responded to treatment. These studies indicate that a parent's anxiety reduces with the reduction of anxiety in their child and that the anxiety they experience may be related to the severity of their child's anxiety.

This study aims to explore parent's perceptions of anxiety in order to inform the development of future treatment for anxiety in children with ASD.

The interviews focused on three main areas:
1. Parent's experience of their child's anxiety
2. Parent's experience of their own psychological well being in looking after their child
3. Parent's perceptions of how the anxiety has been experienced within the parent child relationship

After the interview if you feel you need additional support or help either for yourself or your child it would be best to contact your GP. In addition the National Autistic Society is a great resource for further advice and help.

We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

Jo Rosenberg: █████████████████████████

Marina Gulina: ████████████████████

Ethics approval code: *PSYETH (P/L) 15/16 51*

APPENDIX E: ETHICAL APPROVAL

CITY UNIVERSITY LONDON

Psychology Research Ethics Committee
School of Arts and Social Sciences
City University London
London EC1R 0JD

2nd November 2015

Dear Joanna Rosenberg
Reference: PSYETH (P/L) 15/16 51
Project title: Parent's experience of anxiety in the family in which there is a child with ASD.

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval
Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments
You will also need to submit an Amendments Form if you want to make any of the following changes to your research:
      (a) Recruit a new category of participants
      (b) Change, or add to, the research method employed
      (c) Collect additional types of data
      (d) Change the researchers involved in the project

Adverse events
You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee   ), in the event of any of the following:
      (a) Adverse events
      (b) Breaches of confidentiality
      (c) Safeguarding issues relating to children and vulnerable adults
      (d) Incidents that affect the personal safety of a participant or researcher
Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Hayley Glasford   Katy Tapper
Student Administrator   Chair
Email: Email:

APPENDIX F: EXAMPLE OF TRANSCRIPT AND NOTE TAKING FROM INTERVIEW WITH ELLIE

Transcript from interview with Ellie

433 JR: Are there any other kids with autism #0:28:55.8# in the school
434
435 There are some others, I don't know how many but they're not, X is so not typical
436 #0:29:3.6#
437
438 JR: mmm #0:29:4.0#
439
440 I: So...that's the other thing you grapple with because they do a little bit of reading
441 and they say oh yes, he's bound to have problems with this..and he's not going to
442 get this and he's not going to be able to read people's facial expressions. And you
443 think he's not like that, you've got to get to know him (emphasis on him), you can't
444 assume all these things are going to apply to him. So umm, and they did have some
445 offer of sessions from CAMHS and they had one or two but they decided not to
446 respond but he didn't seem able to respond to them
447
448 This was in year 7 he's had help with CAMHS but the school were offering sessions
449 with CAMHS, they had two and they didn't answer any more emails. They obviously
450 didn't want.. #0:29:48.3#
451
452 JR: What help is X having #0:29:50.8#
453
454 I: He's not having any now #0:29:52.9#
455
456 JR: What has he had? #0:29:54.3#
457
458 I: Very little. He had a group with Great Ormond Street umm which was like er I
459 can't remember, six sessions. We had a group for parents with kids with Torrets,
460 and there was the group for kids. Umm and then we went back to CAMHS - we just
461 had the referral to CAMHS, the referral sorry..the referral to the psychology
462 department at CAMHS came through as he developed Torrets and whatever and
463 ..then ....because I contacted Great Ormond Street and they'd agreed to take us on
464 this research programme group thing, treatment for Torrets, we weren't allowed any
465 input with CAMHS while he was having that so it didn't interfere with the results.
466 Then we started going to CAMHS..would have been probably in the end of year 7,
467 mid April. Sometime perhaps, but he didn't engage, he didn't want to go, he ...and
468 that's the other thing, he finds it so stressful, just the idea of going, you then
469 question whether it's worth it #0:31:20.5#
470
471 JR: mmm #0:31:21.0#
472
473 I: We made him go, but we made him go to Great Ormond Street the first time, he
474 was virtually retching in the back of the car trying to open the door he was so
475 frightened of going. ..umm ..Anyway, so we made him go to CAMHS a few times,
476 but he wasn't really able to use it...And he doesn't ...when I first thought about
477 getting him help, because when I worked in CAMHS they used to say...the
478 consultant there used to ..didn't offer anything to kids with Aspergers or autism in
479 between their 6 monthly appointments or whatever because they reckoned they
480 couldn't really use it. When he was in a state we really wanted help for him, but

Handwritten note (top right): The need for her son to be understood

Comment [64]: The need for people to understand her son, and not make judgements about him based on his diagnosis.

Handwritten note: Has has the label impacted on her? How does she feel about it?

Comment [65]: Little help that her son has had

Comment [66]: The difficulty her son had with engaging with therapy, the anxiety he felt getting their, her feelings of "is this worth it?" "how much anxiety does he have to experience?"

Handwritten note (left): forced him to go - then really sick

Handwritten note (bottom right): How did Mum experience this? Wasn't able to use the help

10

481 actually when it came down to him getting help he wasn't able to use it because it's
482 like unless you do something so many times, he can't get a grip on it. #0:32:17.0#

> **Comment [67]:** He wasn't able to use the help

483
484 JR: mmm #0:32:17.4#
485
486 I: You know…it's like it doesn't matter if you talk about or even practice it, the fact
487 is, however many years on from when he first became fearful of school he's still
488 fearful of school even though he goes every day and yes its marginally better but its
489 taken years and years and years of him going. You know what I mean…it doesn't
490 matter how many times you do something he's still frightened of it.. #0:32:46.3#

> **Comment [68]:** Ongoing fear and anxiety of going to school despite having been for som many years

491
492 ummm #0:32:46.8# and I don't know what you do about that really #0:32:49.9#

> **Comment [69]:** Helplessness, what should she do to help her son

493
494 JR: Is that do you think because of the class sizes or the environment or actually
495 he's always going to find something else to be frightened of? #0:33:0.5#
496
497 I: ummm deep sigh…I think it's just anything out of his comfort zone. I think he's
498 made home his comfort zone, and anything outside of is frightening, even going out
499 with friends is terrifying, that at least now he's getting a bit older he cares what his
500 friends think so he'll make himself go out with them but it's only once in a blue
501 moon. #0:33:27.7#

> **Comment [70]:** Anything outside of home is anxiety provoking for him

502
503 JR: mmm #0:33:28.3#
504

Repetition of words 'I'm scared' - emphasises how scared her son is and perhaps how scared she is?

505 I: And then he'll say before he goes "I'm scared, I'm scared Mummy. I'm scared, I'm
506 scared Mummy:#0:33:34.0#

> **Comment [71]:** I wonder how this makes her feel

507
508 JR: Has he got many friends?#0:33:36.7#
509
510 I: He's got…yeah not masses and masses. He's got..there's a group of 3 of them
511 who go round together at school and he's got..umm I think he's quite popular with
512 the other boys. He's a funny boy, he's got a really good sense of humour, a bit
513 wacky. He's obsessed with electronics and computers and gaming, and so he's
514 friendly with people who are obsessed with electronics and computers and gaming.
515 when he first went to the school he had a group of friends that he made quite
516 quickly and some left over from primary, and they were much more they were into
517 the same sort of things but much more geeky #0:34:13.3#

> **Comment [72]:** Describes her son positively, wacky, funny, group of friends

518
519 JR: mmm #0:34:13.9#
520

Mum's pleasure in son's ability to make friends

521 I: …whereas…and they didn't have that sort of sense of humour that he's got, and
522 now he's found his niche with these two other boys. They laugh hysterically
523 together as well which is fantastic. And he's got another….my best friend's son is
524 slightly wacky and they get on well together. But we went out for lunch the other
525 week out of the blue, my friend rang up "ooh does X want to go out for lunch to
526 pizza express, we'll walk over the heath and whatever?". X could not make up his
527 mind to go, he was so frightened of going. In the end the offer was withdrawn and
528 his friend had a tantrum with him cos X had apparently said "I don't know at the

Use of story telling - what the purpose of this?

11

200

529 moment whether I want to go", and X's friend said "well...I really want to go, come
530 on we're going to walk over the heath and we'll go to pizza express", and X says
531 "what time?" and X's friend says "..about 1pm" and X says "sounds good". So then,
532 X's friend thinks that X has agreed to go, and X says "no I haven't agreed to go",
533 I've said "1pm seems like a reasonable time to go out for lunch" #0:35:26.7#
534
535 laughter #0:35:27.8#
536
537 So it became this whole drama, where they couldn't understand where each other
538 were at #0:35:34.5#
539
540 JR: ..and X's friend's not got Asperger's #0:35:37.6#
541
542 I: No no no , X's friend was clear that X had agreed and he didn't understand that X
543 was operating in a very Asperger's way at that time. And er..anyway finally it all
544 blew over and we went out, but he was very scared but once we got there, once we
545 started walking, he was fine. and then on the way back me and my friend called in
546 at Jigsaw and the boys were not amused, they said we thought we were going for a
547 meal not clothes shopping.
548
549 laughter #0:36:7.4#
550
551 I: so anyway X's friend started sliding down the bannister, it just looked ridiculous
552 because although X's friend's 13 and X 14, X is 6 ft 2 and half and X's friend is 6 ft
553 so they looked ridiculous, these long gangly boys who looked about 17/18 messing
554 around on the bannister thing, so anyway so err we said "look if you don't want to
555 wait for us why don't you go on home:, and they said "what walk?", because we got
556 a lift half way there, and er anyway so yes they walked home. They were home
557 after us because they started messing round in the park or heath whatever so it was
558 great, in the end they had the most fantastic time.
559
560 JR: It's just getting him to do it...
561
562 I: Yes... #0:36:52.1#
563
564 JR: And how do you manage though, how do you look after yourself and ...manage
565 all this anxiety, kind of I suppose what's going on for you? #0:37:6.4#
566
567 I: I think it's fine when I'm calm, but if I'm not having a calm day it can really drive
568 me mad.
569
570 JR: mmm
571
572 I: You can't ever be worried about something yourself or thinking about something
573 yourself because he needs to get this contact with you a lot of the time and then it's
574 very hard to have your own thoughts. So then I ended up getting cross...and aaagh
575 (mini scream)
576

[Handwritten annotation near line 558-560: pleasure in her son being out]

[Handwritten annotation near line 570-571: loss of self? No time for self?]

Comment [73]: Insight into the impact of ASD, how her son understands and speaks in a literal way

Comment [74]: Refers to her son's fear

Comment [75]: Emphasis on the need for some head space, the impact that her son's behaviour has on her, how difficult it is to have your own thoughts. Emphasised by her mini scream

12

577 JR: which is completely normal...
578
579 I: well sometimes, yeah but I do feel bad. I find it really hard because I like sleep
580 and he is quite happy to go to bed as late as he possibly can #0:37:53.9#
581
582 JR: mmm
583
584 I: ...and even if we get him in his room, he's keep coming out and wandering
585 around and doesn't want to turn his light off and stuff so it keeps us up mmmmm, so
586 things like that I find hard
587
588 JR: Has it made you feel anxious or depressed?
589
590 I: deep breath....sigh...I've had times when I've found it really really hard, yeah,
591 when he umm when he developed the torets on top of everything else, I just thought
592 oh my gd, I can't deal with this...no I think at times it has made me feel umm yeah
593 really struggle
594
595 JR: mmm
596
597 I: umm because its all been rather relentless. ummm yeah....but I mean now's..
598 now's not so bad, it was when he was just repeating things over and over and over
599 and over again, umm yeah and things like that
600
601 JR: Has that all calmed down now then? It just gradually stopped on its own?
602
603 I: yeah yeah yeah...it all (deep breath)... when we first started the school he was
604 trying to stop his uniform as I was putting it on because he couldn't stand the feel of
605 it and things like that. And there were times we were dressing him to get to him
606 school against his will to get him to school and because you know people might not
607 agree with that. I just felt so strongly that if I had an 11 year old telling me they're
608 not going to school then what am I going to do. If he stops at 11, then I haven't got
609 a hope. So he had to go as far as I was concerned (deep breath), we'd manage it
610 once he got there. I'd go in with him or whatever but I was not going to have him
611 refusing.
612
613 JR: mm
614
615 I: ...because I couldn't...I just...the amount of times he said I'll be home schooled,
616 and I thought no.. no you won't... no...no...it just wouldn't work #0:39:52.3#
617
618 laughter
619
620 I: No ...I mean...I suppose life is easier now he's on the computer a lot of the time,
621 although I hate him being on it so much and that's a constant source of friction but
622 at least it gives us some headspace.
623
624 JR: mmmm how long is he on it for?

Handwritten annotations:

Mothers' feelings?

feels never ending

use of repetition again, emphasing the relentlessness of it all

Feels judged?

Takes control?

In charge

Use of laughter - hiding her true feelings?

The need for space - reference to this again

Margin comments:

Comment [76]: Try to normalise this for her

Comment [77]: How all encompassing it is, how he doesn't go to sleep at night, and this keeps her awake

Comment [78]: Emphasis on how hard it is

Comment [79]: Refers to the struggle shes been through

Comment [80]: Another reference to how relentless she has found it.

Comment [81]: The battle she experienced of getting her son to school. Her feelings of desperation, her feelings of possibly being judged by others in forcing him to go, yet her strong internal belief that he had to go to school, that if she couldn't get him to school then what would she do. It feels that this is her only hope

Comment [82]: This was not an option for him not to attend school for her

Comment [83]: Represents her desperation perhaps, her need that her son attend school and not be home schooled

Comment [84]: Reference again to the need for some headspace

13

use of word battle - represents strong conflict between them

625 I: oh hours...he doesn't want to come off now. It's a constant battle
626
627 JR: so that's his ..safe place
628
629 I: yes yeah yeah it's the thing he's most interested in...it also distracts him
630 completely from his anxiety so while he's on it he doesn't have to be anxious.
631 Ummm as soon as he's off he's in touch with his anxiety again, so he doesn't want
632 to come off it. And it's just gradually become more and more and more a feature, it's
633 so hard to find a way out of it now. Umm just hope that he wants to work in
634 computing, I think he will to be honest, that's the only thing he cares about
635
636 JR: computers..
637
638 I: deep sigh yeah
639
640 JR: It's a source of friction? Is that you want? Him to come off after however many
641 hours and he's refusing?
642
643 I: yea yeah..it doesn't matter how many limits, time limits you have ..just a few more
644 minutes just a few more minutes...you don't understand...(louder voice)..that kind
645 of thing
646
647 JR: It's really hard...it's really relentless on you
648
649 I: mmm it can be, yeah, yeah..
650
651 JR: In what ways do you think it impacts on your relationship with him or if it does I
652 don't know?
653
654 I: ....silence...I just I suppose, he's not always easy to be with, but on the other
655 hand I feel like I don't see enough of him, even though the computer is there and
656 we are in the same room, it's very difficult to have a normal kind of conversation. I
657 was talking to him on saturday...laughter...I was listening to Tony Blackburn top of
658 the poppers and they had sweet on teenage rampage..you probably won't
659 remember, and I was saying to X "oh my gd when I was 10 or 9 whatever I was in
660 1974, my gran came down and we were watching top of the pops and sweet came
661 on, teenage rampage and my gran was saying no wonder teenagers are like they
662 are today", and it sounded so tame...listening to it on saturday. "Do you mind" he
663 said, "I'm trying to enjoy the last of my holiday, would you mind not talking to me"
664 (laughter)...I said oh, alright then.
665
666 JR: Are you finding it harder to have a relationship with him now than when he was
667 younger?
668
669 I: when he was younger, he wouldn't let go of me and that did my head in too, as I
670 couldn't have any headspace at all... but he's gorgeous too, you know..it's not like
671 it's all negative ..but he's....
672 JR: How would you describe him, how would you describe your relationship

Feels stuck /helpless/ what else can she do?

It feels relentless and never ending

What is underlying this story? What is she trying to tell me? The need for her son to actually know her in some way? The need to be able to relate to her son?

Refers to headspace again

describes son positively

Comment [85]: Refers to the disagreement between them, her desire for him to come off the computer, his desire to stay on it

Comment [86]: Computer acts as a distraction for her son

Comment [87]: Raises her voice to emphasise her son's refusal to get off the computer

Comment [88]: Picking up on how relentless it all feels

Comment [89]: Laughs a lot through the interview – shows how she is able to manage how she feels through use of sense of humour

Comment [90]: Refers to how she experienced her son as needy as a child, and refers again to the need for head space

14

203

On the one hand she feels he needs her, she provides support and stability

On the other she thinks the cat would be enough or that he needs the cat + husband as much

stability

673 I: I think we're very close. I am his rock, I am, what you know. I am the person he
674 has to have around. ....but then you could equally say he needs the cat and he
675 needs (my husband) as well....umm because ..we never go on holiday, we don't go
676 out, we don't go away, (sigh) because he can't stand it, and then we used to force it
677 but it just became pointless. the last time we went away was to Southwold maybe
678 (deep sigh) 4 years ago something like that..
679
680 JR: You stopped going away?
681
682 I: yeah because he was in such a state, it was more unbearable being away. The
683 apple juice tastes funny, he feels anxious, he feels ill, he can't eat, he misses the
684 cat, just couldn't stand it. He could not stand it up, can't sleep, just found it so
685 unbearably anxiety provoking umm and we used to just push it and go, but the last
686 time I think we just thought, we can't do it. We got married umm two years ago in
687 May, and we arranged for him to go to our friends who he will only go to one
688 person's house to stay and then that's really frightening for him but he will do it
689 occasionally. But we arranged for him to stay two nights with X's friend and he
690 stayed one, and after that he had to come home. He can't bear it, he can't be away
691
692 JR: gosh...
693
694 JR: so how do you find that? do you find that difficult or...
695
696 I: I think we're more used to it than we were. It used to be much more frustrating,
697 but...(my husband)'s parents are ill, and (my husband) goes to Birmingham on his
698 own now because we can't go as a family..
699
700 JR: Because your son won't go?
701
702 I: yeah...
703 yeah...we don't go anywhere. we don't go anywhere at all
704
705 JR: But your son does occasionally go for a pizza so he does occasionally?
706
707 I: Occasionally, but it's a big drama trying to get it to happen..big sigh. umm yeah.
708
709 JR: Do you and your husband get to go out together or..
710
711 I: more recently. Only now because he didn't want babysitters either, so...laughs..
712 so anyway ummm but now we can leave him for a few hours, but that's a really
713 recent thing. So umm every holiday I used to feel like I was under house arrest, and
714 he didn't want to come out so umm but then if I even deviated
715 from Sainsburys laughter....walk into a charity shop or something, he'd say "no, no
716 we didn't agree to this...", so we didn't go anywhere, we didn't do anything. I went
717 out, (my husband) didn't go out. (my husband) isn't really he's not so bothered
718 about it you know, but we never went out together. So anyway a year ago last
719 summer I started saying "can I just go and get a paper please?", and he'd say "how
720 long are you going to be?, are you going anywhere else?, have you got your

'force' again - making him do something against his will

'I feel stressed listening to this

Repetition, emphasising perhaps how she feels about us going out?

Use of word 'force' again

feels imprisoned in own home

Comment [91]: Use of the word rock, really highlights how she is there for him, how supportive she is towards her son

Comment [92]: Impact of her son's behaviour on her life – no longer goes on holiday, doesn't feel able to go out

Comment [93]: The impact of the anxiety on her son and their family

Comment [94]: Her son's desire to stay at home

Comment [95]: Her acceptance of the situation

Comment [96]: Feeling of being trapped in the house

Comment [97]: The control that her son exerts on her life

Comment [98]: Laughter again

Role reversal in their relationship. Who is in charge?

What control does she have over what she wants to do? Loss of self in role of motherhood? Sense of loss, how does this make her feel?

How unbearable must it be for this mother to be unable to go out? How different is this to how she imagined motherhood might be? How does it make her feel? Feeling the love for her son against what she might have hoped and wished for? It makes me think of the loss of shattered dreams.

204

I feel anxious listening to her and thinking about how this must be

721 phone?". laughs...so he started some days letting me get a paper, so we built on
722 that and now....we can ... we went out for a couple of hours on friday night just to
723 the bull faced stag but yeah...so now we're allowed to do that, so we can go out
724 sometimes
725

Comment [99]: The word "allowed" – her son has full control in their household – almost that he is the adult, and she the child

726 JR: so he completely controls what you do really
727

Comment [100]: Suggests how her son's behaviour has dictated their lifestyle and controls what she can do, where she can go etc

728 I: ummm yeah.. and I know that sounds like we should have been able to do
729 something about it but it's been impossible to
730

Comment [101]: The feeling that she should have been able to do something to help manage the anxiety, but it's been too difficult to do so

731 JR: It sounds impossible...
732

sense of helplessness

733 I: I don't know..and when you look at the anxiety he goes through, i don't know what
734 you're meant to do about it. we insist on things, we insist on him going to school
735 despite his anxiety, we insist on him we went to see simple minds in concert in
736 november and we told him he had to have a babysitter and err he accepted it
737 although he accepted it but he started panicking that we were going to get blown up
738 on the tube, so he was texting me are you safe, are you there blah blah and he
739 managed it and that was great but its not something we could do very often ....
740

Comment [102]: Refers again to how she doesn't know what she should have done.

Comment [103]: The dilemaa she has – the extent of his anxiety levels are so high that she feels she insists he goes to school and does his homework but doesn't feel able to insist on him doing anything else

741 JR: Have you coped emotionally then? Not being able to go out? Dealing with his
742 constant anxiety?
743

744 I: I've found it really hard at times..really really hard err yeah
745

loss of control / lack of choice

air feelings of anxiety

746 ummm but it's ...well....I don't really have a choice...haven't really ....sighs
747 ummm....yeah i mean and he does make you anxious, he does make you worry
748 about him and worry about the future and all that kind of stuff as well
749

Comment [104]: Her worries about her son's future

750 JR: mmm do you worry a lot about his future
751

752 I: I think on a day to day basis i am more caught up with just him generally...
753

Comment [105]: Refers to how she lives day by day, how he takes up her time on a daily basis

754 mmmm he really ..he does so little for himself. he does virtually nothing for himself,
755 sighs...you ...you know when you're before you're a parent, you really think my
756 child will never do that.....laughs. ...my child will never do that but you have one
757 thats very unique laughs. and you do every bloody thing for them. I really don't know
758 what you're meant to do...because if you could see him, if you could see how white
759 he goes, how physically ill it makes him and i do feel i think we got in to this thing
760 the other year when we felt like, we're forcing him to go to school every day, we're
761 forcing him to go through that anxiety because he absolutely has to go to school

Comment [106]: His dependence on her

Comment [107]: Laughter perhaps about the naivety of what you think before you become a parent

Comment [108]: The physical impact of his anxiety on him

Comment [109]: Refers again to not knowing what you should do. Is there an ongoing dilemma, that she feels she should be doing something differently but doesn't know what

762
763 JR: mmm #0:49:22.1#
764

How much can they force her son to do? And at what cost?

765 I: He doesn't have (emphasis) to do other things and is it fair that we force...you
766 know he can't have his whole life feeling like a nightmare #0:49:31.8#
767

Comment [110]: The dilemma of what she should make her son do given the huge anxiety that he experiences

768 JR: mmm #0:49:32.1#

How far should she push him and at what cost? Seems to be internal dilemma as to what she should do, given the anguish her son then experiences

(left margin handwritten notes)
sense of desperation – what can she do??

sense of desperation

The dis distress she feels for her son

16

205

APPENDIX G: INITIAL NOTES FOR ANALYSIS OF INTERVIEW WITH ELLIE

Use of laughter – participant perhaps uses humour to reflect embarrassment of what she perceives to be her shortcomings or perhaps to reflect understanding of the difficulty of the situation.

Expectation to be able to manage her child's tantrums and behaviour. The sense of being judged and feeling unable to do so, and feelings of incompetence perhaps in being unable to resolve the behavioural issues of her child.

Sense of helplessness, the feeling that she should have been able to sort out the problems but was unable to do so.

Her son's total fear of going to school, her belief that this anxiety is part of the Asperger's as otherwise he would have managed to overcome this fear.

The triggers for her son's anxiety – bullying at school, the difficult teacher, being unwell at school and unable to get help.

The increasing anxiety that her son experienced from this point in time and how everything had seemed normal up until this point. Reference to the terrible tantrums and the constant talking, but the unawareness at this stage that anything was wrong.

The impact of her son's increasing anxiety at junior school, how he begun to refuse to go alone to playdates, to leave the house, to go on holiday, to return to school after holiday.

The increasing anxiety at this time, how it worsened after going on a school trip.

The family's ability to manage at this time, but how it hit breaking point once these Tics developed.

The ways in which the anxiety was taking over their lives. the all encompassing nature of the anxiety. Seems that the anxiety is the problem, not other aspects of the Aspergers.

The lack of help available. The difficulty getting support. The increasing anxiety and impact on the tics, on her son's behaviour at this time.

The difficulty in believing the diagnosis, the dilemma that part of her believed it could be AS, and the other part really didn't think it was. The length of time it took to get a diagnosis, and then the lack of help that was made available to them.

The feeling of not being heard, listened to or understood by the medical profession. The need for help with his anxiety, but the anxiety was seen as part of the AS and untreatable.

The lack of headspace, the all encompassing nature of her son's anxiety so that she feels she cannot think. The need for her son to stop, to give her some space.

The love she feels for her son, how he is engaging, funny, quirky, good sense of humour, able to make friends, make eye contact, how he wanted to seek people's attention as a young child. His high ability as a child, the lego that he built from a young age which was suitable for a much older child.

His lack of empathy which concerned her, and his difficulty in having empathy for others now.

Her annoyance at the way in which the AS was diagnosed. Her feelings of helplessness – that he needed help with his anxiety and she was told there would be no help available. That there's no point in giving help to someone with AS.

Her desperation in trying to get help for her son, how her son's anxiety was worsening, and the situation was escalating at home.

Impact of anxiety on her son, his fear of going to school, his development of full blown Torrets after going on a school trip at junior school.

The lack of understanding from his school – the disbelief that her son had AS as it didn't fit people's perceptions of ASD.

Her son's character, his ability to get over the tics himself rather than attend a group.

Her son's anxiety: his fear of going to school, doing his homework in case he gets it wrong, his dislike of leaving the house, fear of going to sleep as when he wakes it will be time for school again, his fear of going on holiday, on trips, of leaving his home – his safe place. The difficulty her son has on focusing on homework, on being able to transition from one task to another. His fear of change and of anything unfamiliar or different to his routine.

Her son's literalness and inability to be able to read between the lines. The impact that this has on his social arrangements, on his ability to do his homework. How he needs everything spelt out for him.

The all encompassing nature of the anxiety, how it takes up every second of the day with him telling her how anxious he is. The way in which his anxiety has taken over their lives and taken control of her life – she no longer goes on holiday, has been house bound at times, has asked his permission to go and get a paper or pop to the shops.

The feeling of imprisonment in her own home. The control that her son exerts in the house.

His feeling of being safe at home. Her role in supporting her son of being "his rock".

The relentless nature of her son's anxiety. Of how she has tried to find solutions to his problems but has been unable to get it right for him.

The inner struggles that she has – how she sees how hard it is for him to go to school, but her underlying belief and need for him to go to school and that this is not negotiable. The extent to which this anxiety impacts on him, how he goes physically white, how he can't sleep and the tantrums he has, the difficulties doing his homework – how all of this is non negotiable for her. But she believes that other aspects are negotiable such as going on holiday, going out, and so she doesn't force him to do these things as she believes that she is putting him through enough pain already.

Her desire for her son to be happy, for him to be understood at school. Acts as an advocate for him, how the school doesn't really understand the extent of her son's anxiety and only see how he is managing, but do not experience his fear and anxiety before going to school or going on a school trip.

Her frustration of her son not being understood – how he is not what you might expect from an autistic child. The need for people to get to know her son and not assume that he will fit the label of autism.

The lack of support from CAMHS, her son's difficulty in engaging in sessions and the lack of help that she has received. The anxiety he experienced before going to groups – made her question whether it was worth making him attend. His difficulty in using the help he was given.

His constant fear of going to school. How this has not improved over time – how anything out of his comfort zone frightens him.

The battles with the computer – may also represent her desires for some headspace and her desire to spend time with her son.

The impact of adolescence, how their relationship is changing over time. He still needs her but perhaps not in the same way.

Her sense of humour reflects how she understands her son, how she is able to laugh at some of the things he says or does and helps her to accept her son's quirky behaviours.

Her son's ability to enjoy himself when he is out, but the difficulty and struggle that she has in getting him out.

Her ability to manage better when she is feeling calm. She talks about the lack of headspace, how the anxiety takes up all of her thoughts, how she can never be worried about something herself. At times she has really struggled to cope.

The relentless nature of the anxiety.

Her son's fear of wearing uniform – how she doesn't know whether she did the

right thing in forcing him to wear it and dressing him against his will. Her feeling of being judged and the need to be doing the right thing, and this being one of the things that she was not prepared to negotiate on with him.

His anxiety on being away from home, the extent to which they no longer go away, visit his grandparents, the difficulty of going anywhere. His dislike of babysitters, so it is only recently that they have begun to be able to go out.

Her helplessness at being able to manage his anxiety – the impact on her emotionally.

Her worries about his future, but that she is more caught up with him on a daily basis.

His total dependence and inability to do anything for himself. Her belief that before you become a parent, you think that your child would never behave in a particular way, and now she finds herself in the situation in which she feels she hasn't been able to manage his behaviour, his tantrums, his anxiety but she feels helpless as to what she could have done. The feelings that she should or could have done things differently.

The lack of support, her isolation in dealing with him and in being able to leave the house.

The impact on her relationship with her husband.

The choice over which things to battle over, the acceptance of not having the strength to battle over everything, and to be less rigid in order to cope. How she has chosen to put up with some things rather than fight over it.

The screaming tantrums and fights when she tries to make her son do something that he doesn't want to do – eg get off the computer when asked.

Her belief that her son will be ok in the future, that he will find a way of being in the world.

Her son's view of being an equal in the house, of being an adult, rather than a

child. His lack of understanding that his parents are in charge and not him. The battle that she has in getting her voice accepted by her son.

The nature of the anxiety, it being part of the AS.

APPENDIX H: NOTES ON EMERGING THEMES FROM ELLIE

The impact of anxiety on her son
How the anxiety has taken over both her her son's lives.

His fear of going to school, of leaving the house, of going on holiday. The physical impact it has on him, his stomach aches, the development of torrets, his difficulties going to sleep, the time spent on the computer.

This has resulted in him controlling what they do, where she goes - *Her subsequent loss of control*

Impact of anxiety on mother
The relentless, all encompassing nature of the anxiety. Her need for some headspace, how his anxiety takes up all of her time.

The choice of what to battle with her son and what to allow him to do. Her non negotiable belief that he should attend school, but other things she doesn't force him to do.

The all encompassing impact the anxiety has on her life. She spoke of being housebound when he was at home, unable to go anywhere. Things have improved a little as he has got older and is able to stay on his own, but she is only able to leave him for short periods of time. The way in which her son has controlled what the family do, the holidays they no longer go on, and the amount of time they stay in. Through his anxiety, Mum took the decision to no longer go out or go on holiday – as it was too painful. The choices the family have taken to work around their son's anxiety – not going to school is not an option, not doing homework is not an option but other things are an option.

The feeling of imprisonment – symbolic loss of control/loss of choice

The isolation she has experienced, the feelings of being imprisoned in her own home.

The impact on how she feels able to cope – when she is calm she feels able to manage his anxiety, but when she isn't she loses her temper and shouts. The

impact of anxiety on her – how she is unable to focus on anything else, how she has no head space for anything.

Her beliefs around what she could/should have done
Helplessness/ her beliefs that she should have been able to manage the anxiety
Feelings of being judged.
The self questioning, what should she do?

Professional help
Lack of professional help/ the difficulty in engaging with the therapy offered.

Impact of the label of ASD
The individuality of the AS, the felt lack of understanding from professionals and her son's primary school. The need for her son to be understood – that not all the labels of AS will necessarily apply to him, you need to get to know him.

Use of laughter
Her use of laughter perhaps represents her embarrassment at not having been able to resolve the situation in some instances together with her understanding and her acceptance of her son and her ability to see the funny things he does.

Other thoughts
- the pride/love she feels for her son
- the delight she takes in the friendships he has developed
- the underlying resilience – she has survived and continues to manage

What really stands out for me?
- the loss of control
- the need for her son to be understood
- the sense of helplessness
- the sense of relentlessness
- the pride/love/resilience she has and feels towards her son
- the isolation – both physically and mentally – she feels alone

EMERGENT THEMES
Feelings of being judged by others The belief that others may be able to do a better job The feeling that she should be able to manage his anxiety but feels unable to do so The belief that others may be judging her The experience of her son's tantrums as a reflection of her parenting skills
Diagnosis Mother's feelings Meaning of the label – the need for her child to be seen as an individual Lack of understanding around the diagnosis The worry about the future, what does the diagnosis mean for her son's future, how will he cope
Lack of help/ support Sense of helplessness Increasing desperation Difficulty of son engaging in therapy when support was available Anxiety seen as part of the Asperger's – nothing that you can do
Pride in her son Underlying love for her son Describes him positively and lovingly
Friendships Son's ability to make friends Engaging with others Again the need to see her son as an individual
Relentlessness of the anxiety The all encompassing nature of the anxiety Lack of space to think for herself Experience of son's anxiety as stressful and anxiety provoking
The desire to be able to manage son's anxiety The sense of not knowing what to do The belief that she should know what to do
Communication with school The need for the school to understand her son Acting as an advocate for her son The need for her son to be understood
The balance of control The control that her son exerts over her life The feeling of being imprisoned in her own home The extent to which her son's anxiety impacts on her life Feeing of being trapped Her desire for her son to attend school, not attending school was not an option The role reversal in their relationship
The friction in the house The battle between herself and her son The battle between herself and her husband

The battle between her husband and her son Underlying conflict in the home
Containment of the anxiety The use of technology as a distraction The need to become less rigid, to allow her son to get away with more to reduce his anxiety and to reduce the tension at home
The questioning of self The question of how far to challenge her son at the cost of then seeing the anxiety he experiences in doing so The belief that she should be able to manage the anxiety

Emergent themes	Original transcript	Exploratory comments	Page/ line number
Feelings of being judged by others	*"I just kept thinking…I'm doing everything I should be doing…and everyone would advise you're not being consistent enough*	Expectation to be able to manage her child's tantrums, sense of feeling judged in being able to do so, perhaps feels it to be reflection of parenting ability	1, 20
Sense of helplessness	*"..you're not doing this…we are ….we are….anyways, we just sort of thought that was our lot..*	Sense of helplessness, they are doing everything they can, a sense of acceptance of the situation. There is nothing else that can be done	1, 23
Sense of desperation	*"..we were really quite desperate ...it was completely taking over our lives*	Impact of anxiety on their lives, sense of escalation and increasing desperation	2, 62
Thinking around possible diagnosis	*"..so I did start to think could he had Aspergers, but then there was a bit of me that really didn't think he did..*	Dilemma of thinking that something was wrong but not wanting to believe it	2, 66
Lack of help with son's anxiety	*"..and wouldn't give us any help with his anxiety in the meantime…"*	Lack of support or help for son's anxiety	2, 75
Lack of space to think	*"..you couldn't think..you know…stop..stop..I can't think..*	Impact of how her son's behaviour seemed to take over her life	3, 106
Describes son as very engaging	*"..very engaging, always had friends, always sought out people's eye contact.."*	Indicative of the individualistic nature of autism, not what you might expect from stereotypical beliefs about autism	3, 113
Lack of help and support	*"..because there's no point giving any help to anyone with Aspergers in terms of anxiety.."*	Lack of help and support available with the anxiety. Anxiety seen as part of Aspergers, and no treatment seems available	4, 169
Sense of desperation and helplessness	*"..so I kept getting in touch with them, please we really need some help because he was completely beside himself so much of the time.."*	Increasing sense of urgency and desperation. There seems to be no help available, and the mother is alone in not knowing how to help her son. Sense of isolation	4, 179

Lack of understanding around the diagnosis from others	*"..they didn't believe he had Asperger's..X didn't fit the mould for him.."*	The need to understand the individual, reflects the nature of ASD, the breadth of the spectrum and the individuality of the condition despite the label	5, 208
Pride in her son	*"..it's quite incredible"*	Expresses how proud she is of her son's achievement in teaching himself not to "tic" anymore	5, 223
Pride in her son	*"..which was quite brave because only 3 or 4 people he knew were going.."*	Speaks with pride about her son, describes him positively throughout	6, 271
The all encompassing nature of her son's anxiety	*"I mean it was just, it's ..so all encompassing when he's anxious…takes up every second of every day with him telling you he's anxious, it's all getting in a state, having tantrums.."*	The all encompassing nature of her son's anxiety, no space for Mum, with the anxiety taking up every second of her day	6, 285
Impact of anxiety on son's behaviour	*"homework is a major problem, he cant get it done, he can't focus, he can't distract himself enough from the computer.."*	The impact of the anxiety on her son's behaviour, the difficulty focussing on homework,	6, 310
Experience of son's behaviour as "hell"	*"..he'll drag it out for hours and hours and hours and if it's not in the clearest detail, if there's any ambiguity to it, life is hell.."*	The impact of his anxiety on Mum, the stress she experiences in trying to help her son do his experience	6, 314
Experience of son's anxiety as stressful, distressing	*"well he screams, he shouts, he says he can't do it. He has tantrums.."*	I begin to experience the mother's stress and anxiety around her son's experience of not being able to do the homework. I feel stressed listening to the mother	6, 319
The need to feel safe	*"I think it's about feeling safe, I think it's about everything being familiar.."*	Mother's belief that her son prefers to be at home where he feels safe, perhaps feels in control of his environment	8, 356
The relentless nature of her son's anxiety	*"we've tried, but umm it's very relentless, it's very hard to pinpoint it enough to make it better.."*	The all encompassing, relentless nature of the anxiety, the not knowing what to do to help her son manage his anxiety	8, 367
The sense of not knowing how to help her son	*"..so it's really hard to use things or to get it right for him.."*	The sense of not knowing how to best help her son, the desire to get it right for her	8, 374

		son, but the challenges she faces in trying to do this	
The difficulty communicating the issues to the school	*"..it's really hard..getting it across to the school at times what the issues are.."*	The mother's need for the school to understand the issues and how hard it is to communicate this to the school	8, 379
Desire for son's happiness	*"..I'd rather he was happier than struggling with all this work issue.."*	Preference for son's happiness over high achievement at school	9, 396
Acting as advocate for son	*"I said, look this really isn't going to work, this is going to make him much more angry with the school.."*	The need to advocate on behalf of her son, her desire for the school to understand her son	9, 407
The need for her son's anxiety and autism to be understood	*"..underpinning all of this is enormous anxiety and everything and all of this control and trying to control people and when he does things it's all about anxiety.."*	The need for the school to understand her son's behaviour	9, 417
Frustration of her son not being understood	*..so frustrating, no clue.."*	The frustration of not being understood, of being judged	9, 432
The need for her son to be understood	*"..and that's the other thing you grapple with, because they do a little bit of reading and they say oh yes, he's bound to have problems with this….and you think he's not like that, you've got to get to know him.."*	The need for people to understand her son, to not make judgements about him based on his diagnosis, to not label him, reflects the individualistic nature of autism	10, 440
The difficulty of engaging with therapy	*"..he didn't engage, he didn't want to go, he..and that's the other thing, he finds it so stressful, just the idea of going, you then question whether it's worth it.."*	The difficulty her son had engaging with therapy, the anxiety he felt getting there, her questioning of self, her feelings of "is this worth it", her stress in experiencing her son's anxiety	10, 467
The difficult in using the help	*"actually, when it came down to getting him help, he wasn't able to use it because it's like unless you do something so many times, he can't get a grip on it.."*	The need for constant repetition, even when help was available, it wasn't useful as it was not often enough, it needs to be constant and repetitive. How can intervention for anxiety in children with autism become more useful?	11, 481

Anxiety of going to school	*"when he first became fearful of school, he's still fearful of school even though he goes every day.."*	The continued anxiety of going to school, how does the mum experience this? What's it like for her to experience this?	11, 487
Sense of helplessness	*"..and I don't know what you do about that really"*	The helplessness the mother experiences, what should she do to help her son manage his anxiety, what can she do?	11, 492
Describes son as having friends	*"I think he's quite popular with the other boys, he's a funny boy, he's got a really good sense of humour.."*	Describes her son positively, wacky, funny, has a group of friends, seems pleased about this, relieved maybe?	11, 511
The need for space to think	*"you can't ever be worried about something yourself, or thinking about yourself because he needs this contact with you a lot of the time and then it's very hard to have your own thoughts..so I ended up getting cross and aagh…(mini scream)"*	Emphasis on the need for some "headspace", the impact that her son's behaviour has on her, how difficult it is to have her own space and to be able to think clearly for herself. This is emphasised by her "mini scream" when talking	12, 572
The experience of son's anxiety	*"I've had times when I've found it really hard, yeah…..I think at times it has made me feel umm yeah really struggle.."*	Emphasis on how hard it is, refers to the struggle she has been through in trying to manage her son's anxiety	13, 590
The relentless nature of her son's anxiety	*"because it's all been rather relentless…umm yeah..but now's not so bad"*	Another reference to how hard and relentless she has found managing her son's anxiety, suggests that she is in a better place now than when her son was younger	13, 597
The desire for her son to attend school	*"and there were times we were dressing him to get him to go to school against his will.."*	The battle she experienced getting her son to go to school	13, 605
The feeling of being judged by others	*"and you know people might not agree with that.."*	The feeling that others are judging her negatively, questioning self perhaps, is she doing the right thing	13, 606
The strong desire for her son to attend school	*"I just felt so strongly that I had an 11 year old telling me they are not going to school then what am I going to do? If he stops at 11, then I haven't got a hope.."*	Strong belief that her son had to go to school, sense of desperation, that she would lose all hope for the future if she was unable to get him to attend school. What would it mean for her if he didn't attend school? Would this be reflective of her parenting, would it mean that she had lost the battle in some way?	13, 607

The need for "headspace", the all encompassing nature of the anxiety	*"I suppose life is easier now he's on the computer a lot of the time, although I hate him being on it so much…but at least it gives us some headspace.."*	Refers again to the need for some "headspace", torn between her desire for her son not to spend so much time on the computer against her own need for some time to herself	13, 620
The battle between son and mother	*"..it's a constant battle"*	Refers again to the battle of her son being on the computer, perhaps also reflective of her inner battle, of not knowing what the best thing to do might be, of wanting her son to be away from the computer but at the same time needing and enjoying the freedom and space that this then gives her	14, 625
The use of technology	*"it also distracts him completely from his anxiety"*	The benefit of technology, the distraction it provides	14, 629
The need for some "headspace"	*"he wouldn't let go of me and that did my head in too, as I couldn't have any headspace at all.."*	Refers again to her need for some "headspace", how she experienced her son as needy as a child and how she desired some space for herself, her need to be able to have time to think away from her son	14, 669
Close relationship with son	*"..I think we're very close. I am his rock, I am what you know. I am the person he has to have around.."*	Her use of the word "rock" highlights her steady presence in his life, how she is always there for him, how supportive she is of her son	15, 673
Impact of son's anxiety on her life	*"we never go on holiday, we don't go out, we don't go away, because he can't stand it, and then we used to force it but it just became pointless…"*	The huge impact of her son's anxiety on her life, how she has to stay at home as her son is unable to manage leaving the family home	15, 675
Impact of son's anxiety on her life, the balance of her son's desires against her own needs	*"just found it so unbearably anxiety provoking and we used to just push it and to, but the last time I think we just thought we can't do it.."*	Balancing her own desires and needs against those of her son. The experience of her son's anxiety perhaps became too much to bear, so that she would rather stay at home than experience his distress	15, 684
Acceptance of the situation	*"I think we're more used to it than we were..it used to be much more frustrating.."*	Gradual acceptance of the situation	15, 696
Feeling of being trapped	*"we don't go anywhere, we don't go anywhere at all"*	Repetition and emphasis on not leaving the house, of not being able to go anywhere, of feeling trapped at home	15, 703

			perhaps	
Feeling of being imprisoned at home	*"so every holiday, I used to feel like I was under house arrest.."*	The control that her son exerts over her life, her feeling of being a prisoner in her own home, creates a powerful image in my mind	15, 713	
Role reversal in relationship	*"I started saying, can I just go and get a paper please?"*	The control that her son exerts on her life, her inability to leave the house, to do as she pleases, her loss of freedom, perhaps indicative of her underlying loss of sense of self.	15, 718	
The balance of control	*" so now we're allowed to do that, we can go out sometimes."*	The word "allowed" suggests that her son controls what she is able to do, a sense of him being in charge. Suggests that her son's behaviour has dictated her lifestyle	16, 723	
The feeling of "should have been able to manage the anxiety"	*"that sounds like we should have been able to do something about it but it's been impossible to.."*	Again, the sense that she should have known what to do, of how to manage her son's anxiety, leaving her feeling helpless in not being able to help her son	16, 727	
Sense of helplessness	*"I don't know..and when you look at the anxiety he goes through, I don't know what you're meant to do about it.."*	The belief that she should be able to help her son manage his anxiety, the not knowing how to help him	16, 732	
Worry about the future	*"he does make you worry about him and worry about the future"*	The worry about how he will manage in the future	16, 747	
Sense of helplessness	*"I really don't know what you're meant to do, because if you could see how white he goes, how physically ill it makes him .."*	The physical impact of the anxiety on her son, how the mother experiences her son's anxiety, the helplessness she feels	16, 756	
Questioning self	*"and is it fair that we force..you know he can't have his whole life feeling like a nightmare.."*	Questioning the extent to which she should push her son to do things he doesn't want to do, given the huge anxiety he experiences, her distress in experiencing his anxiety	16, 764	
The battle between her and her son	*"I'm not sure we've got the strength to keep battling things over we don't have to battle over and I think that's probably how we've coped"*	The ways in which she has managed his anxiety, how she has felt the need to be less rigid so that she can manage better, refers to the word "battle" again, gives the impression of a fight between herself and her son	17, 804	
Questioning self	*"I'm not sure it's necessarily the best, but then I don't think*	Unsure of what is the best way to manage her son's anxiety, but found her own	17, 815	

	its best to have him always feeling…tensions..”	way to cope	
Feeling judged	*“you always think other people could have done it far better..”*	Reference to others doing it better than her possibly, feeling of being judged, that she should have been able to manage	18, 824
Tension within the home	*“he's far more rigid than I am and we do argue over it”*	The discrepancy between her and her husband as to how to best manage their son	18, 842
Tension within the home	*“I'd rather try and avoid the fights, because the fights..they're not as bad now actually, but they did used to be dreadful”*	Refers to the fighting in the house, she experienced the conflict as "dreadful"	18, 847
Conflict in the home	*“it's always been a major battle to get our voices accepted”*	Again, reference to the word battle – how it seems difficult for herself to be hear in the house, and for her son to accept her decisions. Her son's view of himself as an equal in the house.	19, 908
Perception of the anxiety	*“I do see it as part of the Asperger's, I really do..I didn't initially or before he was diagnosed..”*	Belief that the anxiety is part of the Asperger's, not a separate condition	20, 945

APPENDIX K: TABLE OF SUPER-ORDINATE THEMES AND THEMES FROM INTERVIEW WITH ELLIE

Emergent themes	Key words	Page/ line number
Questioning of self		
The belief that others could do a better job	*"others could have done it far better"*	18, 24
The belief that others may be judging her	*"..everyone would advise.."*	1, 20
The question of how far to challenge her son, given the cost of his subsequent anxiety	*"is it fair that we force.. he can't have his whole life feeling a nightmare.."*	16, 764
Struggle for help		
Sense of helplessness	*"I don't know what you do about that really.."*	11, 492
Increasing desperation	*"please we really need some help"*	4, 179
Lack of support	*"there's no point giving any help to anyone with Asperger's in terms of anxiety"*	4, 169
Difficulty engaging	*"he didn't engage, he didn't want to go"*	10, 467
	"unless you do something so many times, he can't get a grip on it"	11, 481
The importance of friendships		
Pride in her son's ability to make friends	*"he's quite popular with the other boys, he's a funny boy, he's got a really good sense of humour"*	11, 511
Relentlessness of living with the anxiety		
The all encompassing nature of the anxiety	*"takes up every second of every day"*	6, 285
Experience of son's anxiety as stressful	*"if there's any ambiguity to it, life is hell"*	6, 314
The balance of control		
The control which her son exerts	*"so now we're allowed to do that"*	16, 723
The feeling of being imprisoned	*"I used to feel like I was under house arrest"*	15, 713
The role reversal	*"can I just go and get a paper please?"*	15, 718
The need for her son to attend school	*"if he stops at 11, then I haven't got a hope"*	13, 607
Tension within the home		

The battle between her and her son	*"it's a constant battle"*	14, 625
The conflict in how to best manage the anxiety	*"he's far more rigid than I am and we do argue over it"*	18, 842
The sense of not knowing what to do	*"I'm not sure it's necessarily the best"*	17, 815
The Diagnosis		
The need to see her son as an individual	*"you think, he's not like that, you've got to get to know him"*	10, 440
Worry about the future	*"he does make you worry about him and worry about the future"*	16, 747

APPENDIX L: ABSTRACTION LEADING TO DEVELOPMENT OF EMERGING THEMES FOR THE GROUP

EMERGENT THEMES
Diagnosis Mothers' feelings - helplessness - shock/desperation - belief that they would now receive help - underlying fear of what the diagnosis would mean?
Meaning of the label The fear that their child would be labelled The need for others to understand the individuality of their child
External manifestations of the anxiety Difficulty going to sleep Fear of going to school Violence/aggression in the home What is the meaning of this for the participant? There is only so much that they can push their child to do The disruption of family life Learnt to understand how to better manage their child/ when to leave them alone
The impact on family life The control that the child exerts over the family The unpredictability The knowledge that there will always be something that is not going the way it should The impact on the siblings All consuming for the mother and child Likened to being imprisoned Unable to go out, loss of freedom, loss of self Expectations of motherhood versus the reality of coping with their child
The relentlessness of living with the anxiety The exhaustion Lack of control/ no choice The all encompassing/ relentless nature of the anxiety The dread, desire to be ill, to escape Stress/anxiety of how to manage the anxiety The unpredictability The lack of time for themselves
Containment The school environment – containing for some children Anxiety provoking for others The use of technology – provides a distraction – but mothers question the extent to which they should allow their child to use technology The question of how far to challenge their child and at what subsequent emotional cost for them and their child

Friendships
The difficulty of making friends
The desire of some mothers for their child to have friends
What it meant for the mothers for the child to have friends
The need for their child to be accepted
The desire for their child not to be judged/labelled
The fear of isolation in the future if their child did not make friends
What it might mean for them if their child was accepted socially, does this then relinquish some of their child's dependence on them?

Isolation
Lack of help
Lack of support
The difficult the child had engaging in treatment
The sense of helplessness, what should they do?
Being alone in managing their child's anxiety
The sense that no-one will be able to help or look after their child
The bearing of full responsibility for their child

Mothers' fears
The future
How will their child live independently?
Will their child be alone?
How will their child manage if they are not around?
Their desire for their child to be independent
Their worries about the vulnerability of their child

The sense of powerlessness and helplessness
The lack of help and support
The desire to be ill to escape
The role reversal
The balance of power
The child in charge
The control the child exerts within the family
The lack of power the mother experiences
The lack of choice

The unpredictability
The impact on family life
Knowing that something will always go wrong
The fear of their child's response
Life is like a "time bomb"
The fear of not knowing what might trigger an outburst
The fear of saying the wrong word
The feeling that there will always be something not right

Feelings/fear of being judged by others
The belief that others could manage
Feelings of embarrassment
Behaviour thought to be a reflection of parenting
Pride in child, and anger towards others for lack of understanding

EXAMPLE 1: MASTER TABLE OF THEMES

1. THE CHILD'S ANXIETY

Triggers
Increasing self-awareness
Transition to adolescence

Relentlessness
Mother's exhaustion
Fear of the child's behaviour

2. LOSS OF CONTROL

Disruption to family life
"imprisoned" in own home
splitting of the family

Unpredictability
Challenging behaviour
Living with a "time bomb"

Sense of powerlessness and helplessness
Mother's lack of control in how they would like to live their lives
The question of to what extent to "force" their child to do something

3. RELATIONSHIPS WITH OTHERS

Relationships within the home
Conflict in relationships between mother and father, parents and child
Relationships with siblings

Relationships outside the home
Difficulty making friends
Isolation
Mother's desires

4. MOTHER'S FEELINGS

Diagnosis and the future
Worries about the future
Meaning of the diagnosis

Stigmatisation
Fear of being judged by others
Embarrassment

Resiliance
Pride
Love
Containment of anxiety

EXAMPLE 2: MASTER TABLE OF THEMES

1. THE NEED FOR ACCEPTANCE

Diagnosis and worry about the future
The shock of the diagnosis
Coming to terms with what the diagnosis meant for the future
Uncertainty around the future

Stigmatisation/ blame
Feeling of being judged by others
Blamed for child's behaviour – implication on their own parenting
Embarrassment

Relating to others
Desire for child to be accepted by others
Desire for child to form friendships

2. MOTHERS' INTERNAL STRUGGLE

Beliefs regarding role as mother
Adjustment of expectations as mother
Desire to be able to "fix" the anxiety and autism

Containment
How to best manage and contain child's anxiety
To what extent should they challenge their child?

Fight for help
Struggle to access help for child
Difficulty of engaging with therapy

Relentlessness
Mother's exhaustion
Fear of the child's behaviour

3. CONFLICT WITHIN HOME

Disruption to family life
"imprisoned" in own home
splitting of the family

Unpredictability
Challenging behaviour
Living with a "time bomb"

Relationships within the home
Conflict in relationships between mother and father, parents and child
Relationships with siblings

Sense of powerlessness and helplessness
Balance of control between mother and child
Overwhelming sense of helplessness felt by mother

FINAL MASTER TABLE OF THEMES

1. MOTHERS' INTERNAL STRUGGLE

Mothers' inner turmoil
Desire to be able to "fix" the anxiety
To what extent should they challenge their child and at what emotional cost to the child?

Fight for help
Struggle to access help for child
Difficulty of engaging with therapy

Relentlessness of living with their child's anxiety
All encompassing living with the anxiety
Mothers' exhaustion

2. LOSS OF SELF

Balance of power
Fragmentation of family life
The balance of control between mother and child

Living with unpredictability
Challenging behaviour
Living with a "time bomb"

3. OVERWHELMING SENSE OF TENSION

Self blame
Felt blamed by others
Felt child's behaviour to be reflection of parenting ability

Desire for acceptance
Desire for child to be accepted by others
Desire for child to form friendships

Desire for harmony within relationships within the home
Conflict between self and husband
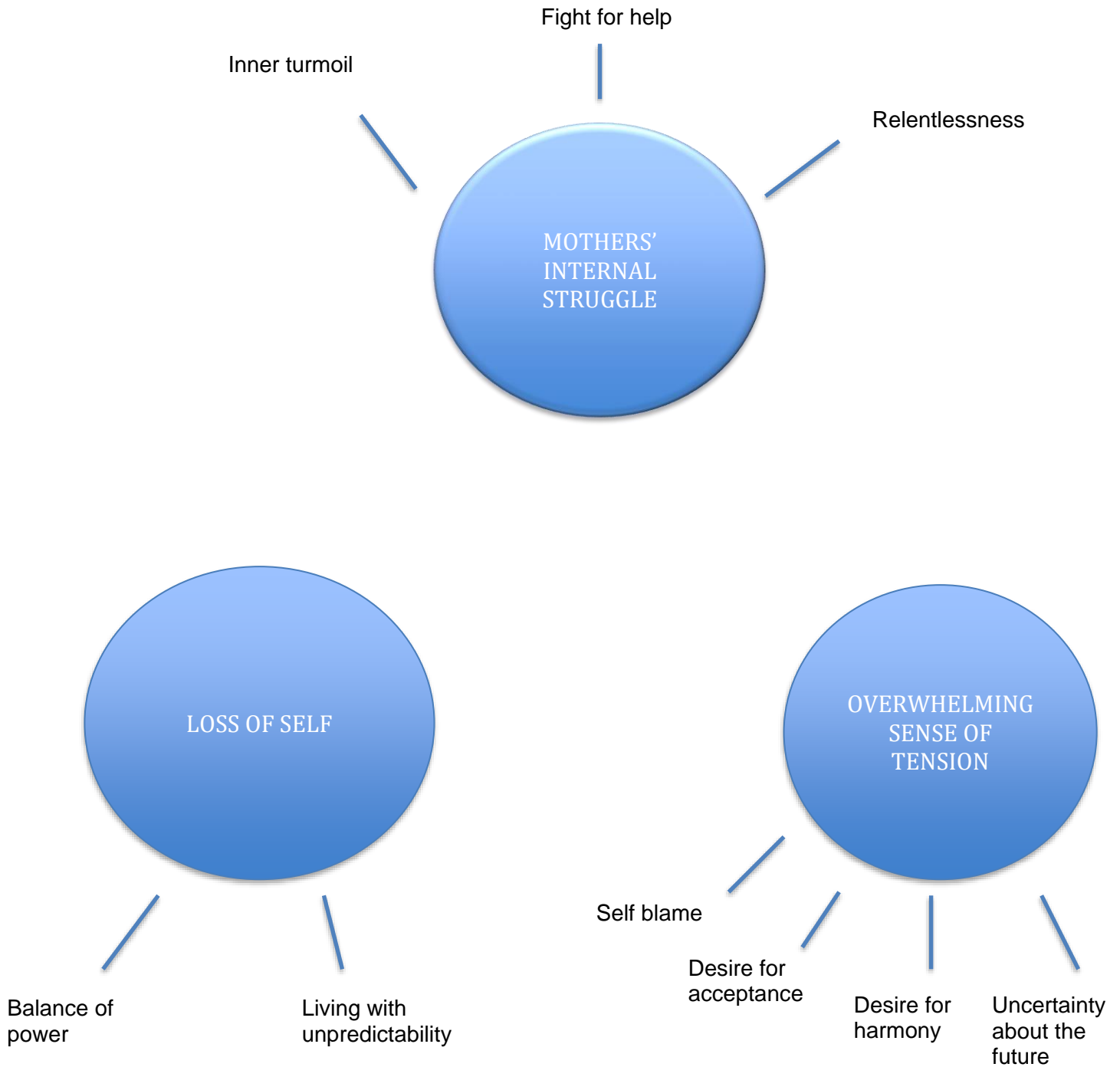Conflict between husband and child
Role of mediator

Uncertainty about the future
The meaning of the diagnosis for their child's future
The desire for their child to be able to live independently

THEMATIC MAP OF FINAL THEMES

Fight for help

Inner turmoil

Relentlessness

MOTHERS'
INTERNAL
STRUGGLE

LOSS OF SELF

OVERWHELMING
SENSE OF
TENSION

Self blame

Balance of
power

Living with
unpredictability

Desire for
acceptance

Desire for
harmony

Uncertainty
about the
future

Emergent themes	Key words	Page/ line number
MOTHERS INTERNAL STRUGGLE *Mother's inner turmoil* Emily:	*"because I'm his Mum, I should be able to do everything for him"*	15, 729
Ellie:	*"when you look at the anxiety he goes through, I don't know what you're meant to do about it"*	16, 732
	"its not necessarily the best, but then I don't think it's the best to have him always feeling tensions"	17, 815
Charlotte:	*"I probably should do more of that but then he'd probably be more anxious"*	10, 466
Grace:	*"then I'll try to fix or try to deal with it"*	7, 345
Anna:	*"I think well good for you, be yourself and be happy. But he's not very happy"*	9, 446
	"I keep really busy..otherwise I would go a bit mad"	9, 458
Amy:	*"it was like a heart breaking inevitability"*	16, 770
Fight for help Ellie:	*"there's no point in giving any help to anyone with Asperger's in terms of anxiety"*	4, 169
	"but he didn't engage, he didn't want to go"	10, 466
Sophie:	*"our biggest thing was that nobody supported us with dealing with his violence"*	14, 732
Charlotte:	*"I don't think you can do it on a once a week basis with him, it sort of has to be an ongoing thing which he's sort of got at school"*	15, 764
Emily:	*"it's not easy to get into CAMHS..but you know I drove them mad…"*	7, 318
	"not really, I mean I have my friends, I don't like talking about it too much…no one likes to hear.."	11, 528

Relentlessness of living with the anxiety		
Sophie:	*"so its exhausting our day..it's kind of this constant.."*	19, 1022
	"I remember I used to think like I almost used to wish I was ill, I would be ill so that I wouldn't have to deal with it"	15, 808
Ellie:	*"it's so encompassing when he's anxious..takes up every second of every day with him telling you he's anxious"*	6, 285
Anna:	*"we'll start again tomorrow, because actually I start to go a bit mental"*	6, 289
Emily:	*"it's draining, it really is draining"*	19, 919
LOSS OF SELF		
Balance of power		
Anna:	*"because actually to try to do something with all of us is.."*	13, 611
Sophie:	*"unless he wants to go somewhere I can't take her"*	20, 1049
	"when he was in a rage, he was properly strong, stronger than me"	13, 671
	"it's like we were living in a house where there was domestic violence for a year"	13, 713
	"it was a constant feeling of worry and sadness.."	16, 848
	"he always went into school"	8, 422
Ellie:	*"I used to feel like I was under house arrest"*	15, 713
	"I really don't know what you're meant to do"	16, 756
	"can I go and get a paper please?"	15, 718
	"if he stops at 11, then I haven't got a hope"	13, 607
Living with unpredictability		
Anna:	*"if I say the wrong thing it can lead to a massive meltdown"*	6, 298
Sophie:	*"you can't predict either..what's going to make him annoyed"*	19, 1010

Amy:	*"if he started to get angry, my other children would literally just disappear upstairs"*	10, 485
Emily:	*"it's like living with a timebomb"*	9, 418
Charlotte:	*"he doesn't always react in the same way to the same noises"*	6, 286

OVERWHELMING SENSE OF TENSION *Self-blame*		
Sophie:	*"you get people like shaking their heads or tutting"*	20, 1062
	"I find that difficult as well because he looks normal"	20, 1061
Ellie:	*"everyone would advise"*	1, 19
Charlotte:	*"initially when he had these outbursts it was very embarrassing"*	7, 342
Amy: *Desire for acceptance*	*"I don't feel embarrassed, I feel intensely proud of him"*	16, 769
Sophie:	*"I'm happy as I am, but you know, I'm not convinced about that"*	9, 482
Anna:	*"why would you think I'd want to go there? I kind of think I don't know, but then he isolates himself"*	11, 512
Ellie:	*"they laugh hysterically together as well which is fantastic"*	11, 512
	"you think, he's not like that, you've got to get to know him"	10, 440
Emily:	*"I was just so grateful that he's got a friend like that that really gets him"*	6, 267
Grace:	*"I think it' helped because there have been other children similar to him"*	10, 462
	"it might seem a bit cruel to almost stop them doing, but it felt it was making him look different"	18, 903
Amy:	*"I genuinely feel grateful that I don't have to experience X feeling sad that he doesn't have friends. Friends are not part of his life"*	14, 714

Charlotte:	*"so it's not that he's not got anyone or that he's lonely"*	8, 396
Desire for harmony within the home		
Anna:	*"it's a huge strain with him and X"*	13, 650
Sophie:	*"he would get really angry and I would be trying to say calm down"*	13, 683
Ellie:	*"they end up in a screaming match with me saying stop"*	18, 844
	"I'm not sure we've got the strength to keep battling things over"	17, 804
Uncertainty about the future		
Anna:	*"my worry with him is that he'll be on his own"*	18, 908
Sophie:	*"I think that the hardest hardest thing that it's forever"*	17, 919
	"there's always something, there's always some aspect of his life that's not quite going the way it is supposed to"	16, 860
Emily:	*"I'm worried about his future because he's vulnerable"*	2, 85
	"I'm very worried about him getting depressed as he's getting older"	10, 472
Grace:	*"I worry about what the future holds for him"*	24, 1185
Amy:	*"it's a gradual sort of, almost like a bereavement, where you are grieving for the life that your child's not going to have"*	3, 122

PART TWO: JOURNAL ARTICLE

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"I USED TO FEEL LIKE I WAS UNDER HOUSE ARREST":

MOTHERS' EXPERIENCES OF CARING FOR THEIR CHILD

WITH AUTISM AND ANXIETY

Abstract

This study explored how mothers make sense of parenting their child with autism and anxiety in order to inform the development of future intervention for anxiety in children with autism spectrum disorder (ASD). Using the method of Interpretative phenomenological analysis (IPA), seven mothers of autistic boys aged between 10-16 years were interviewed. The findings consisted of three master themes: mothers' internal struggle, loss of self and overwhelming sense of tensions. The findings highlighted the emotional stress, anxiety and exhaustion that these mothers experienced in relation to managing their child's anxiety. Their sense of helplessness and inner turmoil was evident in the ways in which they adapted their lives to accommodate their child's needs. The findings suggest the need to consider the mothers' emotional well-being together with those of her child when working with families with autism. Implications for counselling psychology together with suggestions for future research are discussed.

Keywords: autism, anxiety, mothers' experience, interpretative phenomenological analysis

EXPLORING A MOTHER'S LOW SELF-ESTEEM USING A

COGNITIVE BEHAVIOURAL APPROACH

The Professional Practice Component of this thesis has been

removed for confidentiality purposes.

It can be consulted by Psychology researchers on application at

the Library of City, University of London.