

## **PART TWO: JOURNAL ARTICLE**

### **“I USED TO FEEL LIKE I WAS UNDER HOUSE ARREST”: MOTHERS’ EXPERIENCES OF PARENTING 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**

## **Introduction**

Autism spectrum disorder (ASD) is a neurodevelopmental disorder defined by deficits in communication and social interaction, and the engagement in restricted and repetitive patterns of behaviours (American Psychiatric Association, 2013). 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). Research comparing the rate of anxiety in typically developing youth to other groups of youth, suggests 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 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 parents of children with ASD may therefore experience higher levels of anxiety and depression (Estes et al., 2013). Schieve, Blumberg, Rice, Visser, and Boyle (2007) suggest that for parents of children with ASD, their parenting stress was “unique” (p.121), with parents reporting constant, unrelenting challenges, and feeling in an intense state of worry. Studies suggest that parents adjust their lives in order to accommodate their child’s behaviour feeling unable to change the behaviour in any other way (White, McMorris, Weiss, & Lunsky, 2012). Dillenburger, Keenan, Doherty, Byrne & Gallagher (2010) report that parents of children with ASD are nearly three times more likely to be susceptible to experience emotional distress and psychological ill health than the general population highlighting the vulnerability of this population of parents. Given the

increasing number of children being diagnosed with ASD, parental mental health is of paramount importance in being able to support and manage the needs of their children.

Parents of children with ASD experience significantly higher parenting stress (Rao & Beidel, 2009; Hayes & Watson, 2012) 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. 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. The severity of the condition (Abbeduto 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.

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 adolescents with ASD may be even greater. 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, which 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).

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 higher functioning children with ASD, but it is not yet clear which modifications would be most appropriate. Ozsivadjian and Knott (2011) also 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. At the moment clinicians lack clear guidelines

as to which would be the most effective interventions when working with children with ASD and anxiety (Oszivadjian & Knott, 2011).

Children with ASD especially benefit from parental involvement (Burrell & Borrego, 2012), parents being particularly important as they are able to implement continuous treatment (Koegel, Bimbela & Schreibman, 1996). 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 there being significant benefits for the parents themselves and the children (Chalfant, Rapee, & Carroll 2007; Sofronoff et al., 2005; Wood et al., 2009). Studies have indicated that 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). 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). 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).

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, Oswald, Ollendick & Scahill, 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.

In clinical settings anxiety related concerns are among the most common presenting problems for school age children and adolescents with ASD (Ghaziuddin, 2002). It is currently unclear as to what intervention is most effective in treating anxiety in children with ASD, CBT showing some promising results in reducing anxiety in children with autism (eg Reaven et al., 2015). The research highlights the importance of considering parental anxiety and the impact that this may have on the outcome of treatment for their child (eg Conner, Maddox & White, 2013).

The research on anxiety in children with ASD has been largely quantitative in nature. In one of the only studies on parental perspectives on the nature of anxiety in children with ASD, Ozsivadjian, Knott and Magiati (2012) noted that parents reported the impact of anxiety was often more substantial than the impact of ASD itself. 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.

The study is specifically interested in understanding and gaining insight into the mothers' experiences of their autistic child's anxiety and explores how mothers make sense of the experience of parenting their child with autism and anxiety. This study aims to increase our understanding of how mothers make sense of

their child's anxiety in order to inform the development of future treatment for anxiety in children with ASD.

## **Method**

### *Methodological approach*

Interpretative Phenomenological Analysis (IPA) was used to explore how mothers make sense of their experience of parenting their child with autism and anxiety. 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, Flowers & Larkin, 2009). 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.

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). The researcher's interpretation is tentative, and suggestive of the possible underlying meaning of the participants account.



### *Recruitment*

Participants were recruited through a local primary school that has a small number of autistic children attending, and via the method of snowballing. Prior to the interview, participants were given a consent form to sign to indicate that they were willing to participate in the research.

### *Participants*

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 ASD and one child had also been diagnosed with severe anxiety. 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.

### *Procedure*

Seven mothers of autistic children aged from 10-16 years were interviewed using semi-structured interviews. In constructing the questions for the interview schedule, open-ended questions were used to allow the participant to speak freely about their experiences. Prompt questions were used to help participants expand their answers.

All interviews were carried out at either the researcher or participant's home in a quiet and confidential space in which the participant felt comfortable to speak openly and freely. Interviews lasted from 60-90 minutes and time was allowed for the participant to de-brief at the end of the interview.

### *Recording and transcription*

Each interview was recorded using a digital recorder and recordings were stored in both a locked drawer, and on a password protected home computer in accordance with data protection legislation requirements (BPS, 2010).

Interviews were transcribed using software that enabled the pace of the dialogue to be slowed down and words to be accurately transcribed verbatim.

### *Ethical considerations*

This study adhered to the BPS code of ethics and conduct (2010) and ethical approval from City, University of London, was obtained. Participants were given an information sheet prior to the interview explaining what would be involved in the research and that they could leave the process at any point should they so wish. Informed consent was gained from participants at the beginning of the interview. Confidentiality was adhered to throughout the process, with all identifying names and ages 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. At the end of the interview, time was allowed to debrief, and suggestions made for further support offered.

### *Data analysis*

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

Interviews were initially transcribed and all names of participants were changed to ensure confidentiality. To protect and maintain confidentiality each participant

was given a pseudonym. Transcripts were read and re-read and initial notes written on the left hand side of the margin. Transcripts were re-read a second and third time, with notes taken in black ink that were of a descriptive nature, red ink to comment on a linguistic level, and green on a conceptual level. Emerging themes were developed through initially listing out possible ideas, which were then grouped together underneath possible headings. Connections across themes were explored. This process was repeated for each transcript, with a week left in between to enable ideas from each transcript to be bracketed to one side. In the final stage of analysis, connections between cases were identified and lists of master themes together with subthemes were represented in a master table.

## **Findings**

This section describes the themes and subthemes that were identified from the process of analysis.

- “...” indicates that the participant has paused
- [...] indicates words missing in the transcript.

### ***Mothers' internal struggle***

The mothers seemed 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 perhaps serving to exacerbate the exhaustion that these mothers experienced.

### *Inner turmoil*

Underlying the mother's angst seemed 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. There seems to be an expectation that in their role as Mum, they should be able to "fix" the problem, and know how to manage their child's anxiety. There seems to be an increasing sense of desperation in not knowing how to help which is perhaps exacerbated in the beliefs that they should be able to resolve their child's difficulties. The uncertainty of how best to help their child leaves them feeling anxious and frustrated in their desire to protect their child from experiencing this pain. The perception of motherhood is all encompassing, and one in which the mothers' responsibilities are limitless.

*"..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..." (Emily p.15, 729)*

*"..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....(Ellie, p.16, 732).."*

The question of how much to "push" their child arises and it seems that the mothers grapple with the extent to which they feel able to do this, feeling responsible for the anxiety that their son may subsequently experience and unable to bear the extent of their pain. The struggle within the mothers may

reflect their need for their own life at the cost of seeing the anxiety their son then endures. One mother spoke of how she no longer goes 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”. (Ellie, p.15, 182)*

Another mother questioned the extent to which she should challenge her son, worrying that he could be achieving more but fearing 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” (Charlotte, p. 10, 465)*

#### *Fight for help*

The mothers spoke of their struggle to access help for their children, and when they were able to access support, faced the difficulty of their child not necessarily being able to engage with the support offered.

One mother spoke of her attempts at reaching out for support for her son and her feelings of desperation in not knowing how to help him. Underlying this seems to be an increasing sense of despair and isolation in her struggle for support for both herself and her son.

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

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.

*“..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 and her husband she had not received any support in how best to

manage his behaviour. It seems that her helplessness in being able to stop her son's violence may have mirrored the helplessness and isolation she felt in trying to manage the situation alone.

#### *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. The need to provide constant emotional support to their child and the extent to which the mother experienced stress in doing so was evident. The mothers exhaustion and helplessness in being able to manage their child's behavior left them in desperate need of a break, one mother desiring that she could be ill in order to escape from the constant stress.

*"...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.." (Ellie, p.6, 286)*

*"...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." (Anna, p.6, 289)*

*"...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" (Sophie, p.15, 808)*

#### **Loss of self**

##### *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.

One mother likened her son's behaviour to that of "a wild animal". 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 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 down..(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.." (Sophie, p.13,671)*

Others felt like prisoners in their own home, describing the ways in which they felt unable to leave the house, indicative of the loss of freedom that they now experienced. 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.



*“..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)*

### *Living with unpredictability*

This sub theme portrays the unpredictability of their child’s behaviour that the mothers lived with. 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. The mothers spoke of the need to choose their words carefully for fear of provoking an outburst. They described how their child could become angry over seemingly nothing, and one mother likened living with her son to “living with a time bomb”. The strong use of language in the words “time bomb” reflect the extent of her son’s anger that could erupt at any time. The uncertainty of how their child may react left the mothers feeling in a permanent state of tension and stress.

*“...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..” (Anna, p.6, 298)*

*“..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” (Emily, p.9, 418)*

### ***Overwhelming sense of tension***

Underlying this theme seems to be the overwhelming sense of tension that the mothers felt in parenting their child with autism and anxiety, in their roles as “mediator” within the home, and “protector” outside of the home.

### ***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. Their beliefs about how they should or would like to be able to manage their child’s behaviour may be compromised by the way in which they were actually able to manage their child’s challenging behaviour. Feeling judged and blamed by others may cause them to feel increasingly anxious and stressed, perhaps leading them to doubt their competency as a mother.

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

*“..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...” (Ellie, p.1, 19)*

### ***Desire for acceptance***

The mothers also desired for their child to form friendships, which was perhaps symbolic of their own 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.

*".. 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.." (Ellie, p.7, 512)*

The words "*which is fantastic*" perhaps 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.

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

The need to be understood by others is evident. "*..it means the world to him*" perhaps reflects that it not only means everything to her son for be understood by another, but is also of extreme importance to his mother. 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.

#### *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". The mothers described the conflict between their son and husband and the strain that this placed in the family home. The tension

was such that some mothers experienced the weekdays as being calmer. It seems that the burden of responsibility is on the mother to try to maintain peace within the home and do everything she can to prevent the escalation of conflict between others in the home.

*“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 all...it’s a nightmare..” (Anna, p.13, 650)*

*“..he would get really angry and I would be trying to say X, calm down, X, calm down, whilst (my son) was at him and that was really difficult..” (Sophie, p.13, 683)*

#### *Uncertainty about the future*

The mothers spoke of their fears as to how their child would manage and cope in the future. 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. The mothers spoke of their worries about their child’s vulnerability, their desire for their child to be independent and what the diagnosis meant for the future.

*“..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..” (Amy, p.3, 109)*

One mother spoke of her underlying fear 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 burden this may place on her.

*“..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.. [...]....I think what’s really hard is that there’s no one else that can do it...” (Anna, p.18, 908)*

For another mother, 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 ...” (Sophie, p.17, 919)*

The analysis portrays the all-encompassing nature of the ways in which these mothers experience their autistic child’s anxiety within their families. 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.

## **Discussion**

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 highlight the all-

encompassing ways in which these mothers experience their child's anxiety and autism, and the need for professional services to offer further emotional support to mothers of autistic children.

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 over whelming. Studies describe the struggle 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 were seen to be all encompassing, exceeding the demands that mothers of typically developing children may experience (Nicholas et al., 2016).

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); the unpredictable nature of ASD regularly impeding expectation and daily routine (eg. Woodgate, Ateah & Secco, 2008; Nicholas et al., 2016); and the mothers desire for their child to be socially accepted, included and their desire for their child to be able to lead a fulfilling, happy, 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.

This study's 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. The 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 feel they have to adapt and adjust their family's lives to accommodate their child's needs.

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 it's association with parental stress and anxiety may provide insight into how best to help families with autism reduce conflict within the home.

Parental self- efficacy is described as being the extent to which parents view themselves as capable and successful in their parenting role (Giallo, Wood, Jellett, & Porter, 2013). 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. Studies of parental self-efficacy in parents of autistic children have shown an association between parental stress and depression and PSE (Kuhn & Carter, 2006) and 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.

Parental self-efficacy has also been associated with the mother's sense of agency. This is described by Kuhn and Carter (2006) as being the mother's active role in engaging with her child and in being able to identify strategies for her child, together with the mothers' 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. Research suggests that loss of empowerment is associated with higher levels of distress in mothers of children referred to clinics (Scheel & Rieckmann 1998) with families reporting high levels of empowerment more likely to report lower levels of distress.

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.



Much research into parental mental wellbeing 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 et al., 2011). However, studies on the interrelationships between mothers and fathers of autistic children suggest that mothers' levels of stress and depression were predictive of fathers' levels of anxiety and depression and child behavioural problems (Hastings, 2003; Hastings et al., 2005). Garcia-Lopez, Sarria and Pozo, (2016) reported that mothers experience significantly more stress than fathers, with fathers' levels of anxiety being influenced by the mothers' levels of parental self-efficacy. This research suggests the need to move away from focussing on the autistic child as the main predictor of parental stress, and encourages the exploration of 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). Family relationships are seen to be an important factor in influencing the emotional wellbeing of family members (Dallos & Draper, 2010). Studies suggest that family centered 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 experiences. (eg DePape & Lindsay, 2015). 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 through the use of family centered models (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 and systemic practice 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 and highlight the benefits of parental involvement in treatment (eg Chalfant et al., 2007).

This study's findings highlight the need to consider the mothers' emotional needs when working with families with autism. The findings highlighted the emotional distress, anxiety and relentlessness that these mothers experienced in caring for their child with autism and anxiety. Additional professional support is needed to help to alleviate mothers' stress and anxiety in caring for their autistic child. Using an integrative approach consisting of working systemically with the family, together with using specific tailored intervention for the child, may help to promote the emotional well-being of all family members together with those 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.

Although, the use of IPA in this study increased our understanding of how anxiety is experienced within families with autism through the eyes of the mother, there are some limitations that need to be explored. Although the sample of participants recruited was as homogenous as possible, 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. 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. It is also recognised that only mothers have been interviewed for this study.

Future research should include a more diverse sample of mothers of autistic children and should also explore fathers and siblings in order to further our understanding of autism and anxiety within the context of the family experience. Further research could also be undertaken to explore mothers' sense of agency, cognitions and parental self-efficacy in families with autism to further develop our understanding of the mother-child relationship and how these may affect parenting behaviours and the emotional well being of both mother and child.

## **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 burden 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, this study served to highlight the extent of the mothers' inner turmoil and distress in struggling to manage their child's anxiety. This study highlights the need to provide additional professional support to help to alleviate mothers' stress and anxiety in caring for their autistic child. Using a systemic approach with families with autism may help to promote the well-being of all family members together with that of the child with autism. In addition, further consideration of how best to engage the child together with additional parental involvement in treatment, may help to further improve the efficacy of any intervention for anxiety in autistic children.

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