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*"We can still be mother and son, Autism won't stop that..."* A narrative analysis of maternal experiences whilst raising a child with Autism Spectrum Disorder (ASD)

Salma Begum

Supervised by Dr Jo Ashby

March 2015

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## ABSTRACT

Mothers are typically primary caregivers to children on the autism spectrum (Benson, 2012); whilst the majority of research focus primarily on the individual with autism, there is little consideration of the roles of caregivers' and autism creating a gap in the literature. This is a qualitative study exploring the experiences of autism from a maternal perspective.

Five mothers participated in semi structured interviews. The study employed a narrative analysis to identify core narratives involved when raising a child with autism.

The analysis suggests mothers felt a substantial amount of guilt and responsibility specifically in the first year following diagnosis resulting in, eschewing from people around them. Furthermore, the diagnosis prompted mothers in starting their journey towards acceptance, happiness and facilitation of autism into their lives and considering the needs of their child and autism, as a vital factor when enabling their child with a successful start in life.

<b>KEY WORDS:</b>	AUTISM	MOTHER'S	EXPERIENCE	NARRATIVE	SEMI STRUCTURED INTERVIEWS
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## **Autism: A Brief Overview**

Autism is a lifelong neurodevelopmental disorder where symptoms of the disorder typically occur before the age of three and defined under the term Autism Spectrum Disorder (ASD) (Schieve et al, 2007). Child psychologist Leo Kanner initially recognised signs of autism in 1943 in children, who were pleased when left alone, did not interact with others and remained fixated on certain objects (Lai et al, 2014). Individuals with autism have severe impairments with social interaction, communicating and imagination, display behavioural problems and experience delays in their language development (Maaljars et al, 2013; Kral et al, 2013). Children with autism experience communicating with others as problematic, as the disorder can affect the way in which they make sense of their world and the society around them. Research on the effects autism has to children is substantial; however, there is limited research on the impacts of autism in primary caregivers and family life. This research aims to explore the experiences of autism from a mother's perspective, as they are generally primary caregivers (Benson, 2012).

## **Aetiologies and Classifications**

Autism is one of the many developmental disorders classified under the term Autism Spectrum Disorder (ASD), along with Asperger's disorder, childhood disintegrative disorder and pervasive neurodevelopmental disorders not otherwise specified, in the DSM-IV and ICD-10 with symptoms ranging from mild to severe (Lauritsen, 2013). The clustering of disorders into one spectrum is debateable and has been criticised by many researchers. Young and Rodi (2014) found that of those individuals with a developmental disorder, only 57.1% met the criteria of ASD according to the DSM-IV and those with Asperger's disorder were less likely to be diagnosed with ASD. The implications of applying an umbrella term for developmental disorders can affect the appropriate amount of support an individual may require and have a negative impact on the people around them.

There has been an increase in the frequency of autism since 1940 as the aetiologies of ASD have extensively been researched and although no singular cause has been acknowledged, numerous researches suggests genetics have a significant role (Lai et al, 2014). Morrow et al (2008) reported on certain genes that are in an unstimulated position in children with autism, which can be activated through therapies in comparison to others without autism. Specific gene variations such as the nucleotide changes in the AUTS2 gene are associated with autism and other developmental disorders, stating the importance of genetics for neurodevelopment (Oksenberg et al, 2013). The Measles, Mumps and Rubella Vaccine (MMR) controversy suggested occurrence of the vaccine caused developmental disorders in children and later found to have no causal relationship with autism, as the distribution of the MMR vaccine coincides at the same time as initial symptoms occur (Taylor et al, 1999; Farrington et al, 2001).

A growing interest in factors of autism, other than genetics has influenced the production of research, which focus on environmental and social factors and are more likely to understand the aetiologies of autism (Chevallier et al, 2012). Environmental risk factors such as high maternal and paternal age have been identified as a link to disorders on the autism spectrum (WHO, 2013). Mishaal et al

(2014) dispute this as they found no correlation between age of parents and diagnosis of ASD. The vast amount of research has enabled families and healthcare professionals to identify characteristics of ASD as early as possible; this explains the high prevalence as it is estimated 1 in 160 people are diagnosed with ASD worldwide (WHO, 2013).

### **Culture, Society and Autism**

Definitions of autism have altered since initial recognition by Leo Kanner (Lai, et al, 2014) due to the changing cultures and shifts in societal norms. All cultures view autism differently as their definitions of normality and abnormality vary (Kim, 2012). Grinker (2007) suggested disorders and disability are socially constructed within each culture. The social construction theory claims that we exist in a world where meaning has already been constructed, causing inequalities in culture (Scotland, 2012). Cultures originating in the east such as Korea view disabilities to be shameful; therefore, the cultural norm would be to keep the disability concealed from society, as certain disorders are more acceptable in different cultures, which can often lead to a misdiagnosis (Kim, 2012). The shame associated with disabilities in certain cultures can hinder the chances of the disabled individual and their caregiver to integrate and become an active member in society due to the negative connotations socially constructed with developmental disorders such as ASD.

Research into autism has concentrated on cognitive theories, for example, the Theory of Mind (TOM) refers to the way an individual constructs their beliefs and feeling of others (Kim, 2012). Individuals on the autism spectrum are not inclined to construct a TOM similar to those without the disorder (Bovee, 1999), triggering a lack of understanding from society, of individuals with autism as their mind and personality may differ from the social norm in society. Due to the differences in cognition, which are apparent from childhood of those with ASD, as they become adults there is a risk of social isolation and segregation from others in the world around them. Magiati et al (2014) reviewed studies of autism into adulthood and concluded that the outcomes of adults on the autism spectrum were mostly quite poor. The adults typically lived dependently with their parents, with little friends and a lack of a social life. Mothers can also face exclusion because of the rejection of her child from society, Khoadee and Koolae (2011) found 66% of the mothers in their sample, reported very low levels or nonexistence of social function in comparison to mothers of children without ASD due to perceived feeling of exclusion of their child and themselves. Mothers are more at risk of isolation when their child has ASD in comparison to fathers (Johnson and Simpson, 2013). The social outcomes of those with a developmental disorder and their mothers could be poor due to the social construction surrounding autism, restricting integration into society and resulting in exclusion.

Mothers, throughout history have been perceived as culpable to their child's disabilities due to theories of attachment, much emphasis is placed on the expected amount of bonding between a mother and her child (Brockington et al, 2006). The issue of bonding has stimulated stereotypes and prejudice of mothers with an autistic child. Stereotypes and prejudice stem from others holding negative preconceptions towards members of another social group and use those to judge (Buunk and Van Vugt, 2008). The preconceptions of autism from society has frequently been those of

blame placed on mothers and her parenting skills, a classic example is of the Refrigerator Mother Theory (RMT) pioneered by Bettelheim (1967). RMT proposed that autistic behaviours stem from a lack of emotional attachment to her child, essentially placing fault on maternal skills. Thankfully, Landrigan (2010) has disproved this as current evidence is leaning towards a genetic cause of ASD as an alternative to a break in attachment.

Mothers are typically perceived in a negative manner in terms of parenting skills in comparison to fathers of those with ASD. Seidman et al (2012) reported a difference in gender characteristics of parents with a child on the autism spectrum. The fathers rated the mothers of having a more rigid parenting style and personality in comparison to their own; mothers' did not identify their own personalities as rigid. The mothers generally act as the primary caregiver, spending more time parenting a child; this concurs with the findings and the mothers may have adopted a more rigid parenting style due to the demands of the repetitive nature of a child with ASD. Yet again, socially constructed stereotypes of mothers may risk isolating mothers of children with ASD. Lee et al (2010) identified five stages mothers experience when trying to accept autism into their life as a primary caregiver; i) denial ii) wandering iii) devoting iv) mind control v) acceptance. Although perceived negative reactions of autism, intensifies the struggle mothers already face with the initial diagnosis their focus shifts to their child and prioritisation of family becomes apparent (Hoogsteen and Woodgate, 2013). The researches above illustrate the key role and hardship mothers experience as a primary caregiver to a child with ASD and the negative attitudes and constructions surrounding autism and parenting can have a detrimental effect on their journey of acceptance.

### **Maternal Stress**

Specific patterns and traits in behaviour of children with autism raise challenges for parental coping strategies and mothers are more prone to experience severe stress (Maljaars, 2013; Serrata, 2012; Johnson et al, 2011). Ozturk et al (2014) research on mothers and fathers of autistic children suggests mothers report higher levels of stress as they participate in behaviours that are more social with their child than the fathers are. Due to the lack of social skills in children with ASD, mothers will evidently face challenges when trying to coach their child into behaviours that are socially acceptable therefore, they are more prone to stress as they spend majority of their time overcoming these challenges.

Stress escalations in mothers are associated with their child's behavioural problems, hyperactivity and abnormality in eating and sleeping (Mcstay et al, 2014; Meltzer, 2011). Fussiness and rejection of certain foods are common in children with autism, which can add to the stress levels mothers are already experiencing when trying to cope with autism itself (Meltzer, 2011). Issues associated with behaviour problems and hyperactivity in children with autism can cause great difficulty for mothers, research suggests behavioural characteristics increase the levels of stress for mothers (Osborne and Reed, 2009; McStay et al, 2014). A multiple regression analysis on mothers with an autistic child, found a main effect for stress and depression with behaviour problems and autism severity of their child (Weitlauf, 2014). The researches above demonstrate the impact behavioural problems have on maternal wellbeing as the mothers may put in great effort to deal with the challenges

of disciplining problematic behaviour. Phetrasuwan and Shandor (2009) correspond with this as they found mothers who had reported high levels of stress and depression, due to behavioural problems of autism had a low level of overall wellbeing. Stress has also shown to increase when parents of an autistic child other without the developmental disorder, Van steijn (2014) reported parents of children with autism, had higher levels of stress in comparison, to the stress when parenting their child without autism. The reflectivity of raising a child without autism can trigger emotion in parents, as they may fear they cannot cope with the challenging obstacles autism has brought in their parenting world. In Hoffman et al's (2010) study, mothers with a child on the autism spectrum reported higher levels of stress than mothers with generally developing children did. The researchers also found that although the levels of stress were related to challenges of autism, the mothers of children with autism still maintained a close and loving relationship with their child, illustrating the strong emotions and relationship mothers maintain throughout hardship. Furthermore, Schieve (2007) found parents had higher levels of aggravation and stress due to the challenging behaviours their children with autism displayed. Depressive symptoms can also occur on mothers due to the challenging role of parenting a child with autism; Jeans et al (2013) found parents of children with autism had more depressive thoughts in comparison to parents of children with typical development. Taking a child outside can also cause stress to mothers due to fears of being judged negatively causing more stress, this can be explained by the fundamental attribution error where assumptions are made based on a single observation (Johnston et al, 2012).

The literature reviewed above has suggested mothers of children with autism, are more likely to be affected in their quality of life and general wellbeing in comparison to fathers. Societal influence has been found to be a factor in the way autism is understood. Therefore, my proposed research question will aim to understand a mother's perspective of autism from a societal viewpoint. The research questions include:

- 1) Based on Grinker's (2007) theory that autism is socially constructed differently throughout cultures, to explore a mothers' perception of how society perceives a mothers role on autism.
- 2) Gain an insight into the experiences of parenting a child with autism whilst trying to adapt to the needs of their children.

## **Methodology and justifications**

### **Objectives**

- Explore the experiences of autism from a mothers perspective
- Look at how mothers narrate their role as a primary caregiver in society
- Delve into how mothers interpret society's perception of mothering a child with autism.
- Allow mothers to narrate their story.

### **Philosophical underpinning**

The Qualitative paradigm adopts a more realistic method of data collection to discover new, insightful research and embraces subjectivity of a researcher instead of rejecting it as a key position (Willig, 2013). Braun and Clarke (2013) suggest Quantitative methods do not allow the truth to emerge and higher quality of information are discovered through the qualitative paradigm.

### **Design**

Semi structured interviews are used popularly throughout qualitative data due to the diversity in the way data can be analysed (Willig, 2013). The nature of semi-structured interviews is to ensure researcher can ask specific questions relating to their aims, allowing the participant to contribute further details into the topic and have more control in their responses (Willig, 2013). An interview schedule (see appendix 5) was devised as a rough guideline of questions the researcher required consistent with research objectives.

### **Interviews**

Qualitative research interviews enable participants to provide as much information they would like to share (Knox, and Burkard, 2009). The interviews with each mother took place at a suitable location both comfortable for the participant and researcher. Participants were given the opportunity to choose the location to ensure they felt as comfortable as possible. Interviews lasted roughly one hour long and participants were debriefed verbally when the interview had finished. The interviews were audio recorded and transcribed ready for analysis.

### **Ethical considerations**

The current research followed the ethical codes of conduct (2009) by the British Psychological Society (BPS). As this research was conducted with mothers of autistic children, the research also followed the code of human research (2010) when considering ethical implications.

Due to the sensitive nature this qualitative research may provoke, the researcher ensured participants gave their fully informed consent prior to the interviews (see appendix 4). Participants were also asked if they would like to continue throughout the interview process (see Appendix 5). The right to withdraw is paramount for any research and mothers were aware of their right to leave the study at any point prior the data collection.

Qualitative research involving interviews may involve personal details such as names to appear, in order to protect the mothers in this study the researcher assigned pseudonyms to any name mentioned. The use of recording equipment for this study involved the storage of interview data. The researcher ensured all audio recording and transcripts were kept in a secure password protected device, and has been destroyed safely after analysis

### **Participants**

Five mothers of autistic children participated in this research and were recruited via a snowball sampling technique (Biernacki, 1981); where participants refer one another. The researcher made initial contact with a mother who then introduced further mothers. The researcher ensured to have contact with the mothers prior to the interview stage to build rapport. Building rapport with participants is essential when conducting interview to make the participant comfortable with the researcher and enhance the quality of the data (Braun and Clarke, 2013).

### **Qualitative research**

As quantitative approaches have been significantly involved in research into autism aetiologies, there is a lack of qualitative data. There is limited availability into qualitative studies aiming to explore other aspects of ASD such as; social and environmental influences, parental wellbeing, quality of life of children with ASD and societal perspectives of developmental disorders (Chevallier et al, 2012).

This study takes a qualitative approach as, qualitative methods in psychology aim to aims to gain rich in depth data of the beliefs people hold and making sense of the data collected and attempts to delve deep into the meanings of the topic being explored (Willig, 2013) The nature of qualitative research is to discover new themes and reflect the stories being told in a detailed manner.

Qualitative research aims to discover deeper meaning and researchers therefore consider their epistemological and ontological position. Epistemology refers to the types of knowledge that already exist and ontology refers to what it means to know the knowledge the researcher is studying (Willig, 2013). As the research aimed to explore the experiences of mothers with an autistic child, the stories mothers told using language to construct their experiences was of importance to the researcher. Therefore, a narrative analysis with a social constructionist position was conducted. The ontological position of this research focuses on critical realism – when we are critical in the way we exist (Scotland, 2012).

### **Narrative analysis**

When relying on stories of experiences a narrative analysis is appropriate as the method focuses on narratives of imagery, tone and language are constructed (Webster and Mertova, 2007). A narrative analysis aims to explore the participants own interpretation of events in their life (Murray, 2003). Emerson and Frosh's (2009) method of narrative analysis stated to conduct a thematic analysis on transcribed data before looking for narratives. This research aimed to discover the participant's narratives of being a mother to a child with autism. The researcher employed a combination of critical narrative techniques consisting of six steps proposed by



Crossley (2000) and Fraser (2004). After reading the interview transcripts several times the steps of analysis included; i) analysing ii) establishing key concepts iii) classifying the narrative tone iv) categorising the key themes, images and tones v) linking the concepts found to gain a rational academic account vi) writing up the final journal report. Narrative analyses allow the narrator (participant) to discuss their stories and interpretations of events in their lives providing rich and detailed data (Crossley, 2000; Fraser; 2004).

## **Analysis and Discussion**

After completion of all five transcripts, key similarities between each transcript emerged along with the many differences. The use of a narrative analysis allowed further innovative and perceptive topics to appear to the researcher. Three core narratives were established through the events told by each mother prior to, during and post diagnosis.

- 1) Dealing with uncertainty: Isolation, Perceptions and Social Identity.**
- 2) Stress: Behaviour and Development.**
- 3) Support, and Drive to Acceptance**

## **Dealing with Uncertainty: Isolation, Perceptions and Social Identity Uncertainty**

**“It’s all the unknown that worries me. A lot of questions I have, there’s no answer so it’s just a wait and see process... (Rebecca, lines 311-312).**

Prior to diagnosis, the mothers expressed their annoyance towards the healthcare professionals and feelings of uncertainty when taking the steps towards a diagnosis. Naomi narrated her uncertainty during the year it took before her son finally received a diagnosis.

**“It was such a long time, I just wanted someone to tell me what was wrong. I hate the fact they kept me waiting, it just made everything worse...” (Naomi, lines 52-57).**

The lengthy process leading up to the diagnosis was particularly hard on all the mothers as the uncertainty caused more feelings of frustration towards healthcare professionals. The emphasis Naomi stressed on “someone” demonstrates her anger as her tone in voice changed from quiet to a more louder and authoritative narrator. The lack of an earlier diagnosis was difficult as the mothers were unaware how to help their child. Osborne and reed (2008) found that parents’ ideally wished to have received an earlier diagnosis. The mothers in this research felt the delayed diagnose disadvantaged their happiness.

**“I knew something was wrong, he hadn’t reached the same milestones as the others but I felt like I was drowning into the unknown...” (Anita, lines 20-24).**

All the mothers had noticed the differences in their autistic child early on due to comparisons with their previous children. Anita creates powerful imagery of her helplessness due to the uncertainty surrounding initial diagnosis. The use of the metaphor “drowning” illustrates the severity of puzzlement she felt initially as the delay in diagnosis pushed her further into anguish. All mothers narrated the year prior to diagnosis as their most difficult moments of feeling lost. McConkey et al’s (2009) research focused on the narration of the signs mothers noticed of autism when they recollect initial memories, the mothers retell their experiences of how comparisons to their other children led to diagnosis, similarly to the mothers in this research discussed.

## **Isolation**

**“I felt lonely, I chose to stay away from everyone because I got stares from people, I chose not to believe his autism because I thought he wasn’t normal (laughs)...” (Lana, lines 56-60).**

It was worrying to hear the prolonged feelings of isolation during the period of diagnosis and post diagnosis. Lana describes her loneliness and isolation from the people around her due to the negative socially constructed views about autism and her denial. Rafii et al, (2012) proposed that denial of the disorder caused further isolation in mothers, which can restrict the possibilities of children with ASD,

integrating into society as the mothers generally accompany the children outside. Lana also creates a light-hearted atmosphere when discussing a time in her life, which was not her happiest through laughter. 'Normal' is continuously used throughout all transcripts as mothers may feel autism is not normal and they are basing their meanings of 'normality' on others around them without ASD. Anita also feels autism is an abnormality in her life, which has affected her previous life prior to autism.

**“I feel like I’m not normal anymore, I can’t do the same things I used to but people don’t understand that...” (Anita, lines 254-255).**

It is common for parents to believe the existence of restrictions autism has on the opportunities for their child (Hines et al, 2012) however Anita similarly explains the feelings of restriction placed on herself due to her son’s autism. This demonstrates the ignorance in society when perceiving a caregiver of a child with autism; it not only affects the child but the person taking care of the child. The lack of acknowledgement of mother’s feelings puts them at further risk of isolation.

### **Perception**

**“The way they spoke to me wasn’t nice, asking me does he always stay up this late, they don’t understand it’s because of his autism! ...” (Rebecca, lines 396-400).**

**“I get the impression they think I’m a bad mother and then it makes me think am I a bad mother, I must have done something to cause the behaviour problems (sighs)...” (Rachel, lines, 213-217)**

It is alarming of how much negative experiences mothers face from people in society due to misconceptions of autism and its causes. After receiving the diagnosis of autism, the mothers noticed an increased interest of their child from others around them on a daily basis. Both mothers have felt victimised and blame due to the perceived feeling of scrutiny on their parenting skills. Rebecca’s tone when explaining why her son sleeps late creates a sense of moving the blame to autism to remind people that she is not to blame for the disorder. Corman’s (2013) theory suggests shifting blame onto autism can help mothers in accepting autism into their lives.

### **Social identity**

**“I’m not the person I used to be five years ago, I felt like my world was collapsing around me, I don’t surround myself with the same people, I’m not interested in the things I liked...” (Lana, lines 200-205)**

Combining the demands of autism with parenting affect mothers and their social identity (Weusten, 2011). Social identities refer to the theory of people categorising their participation in a group (Buunk and Van Vugt, 2008) and are established via intergroup relations (Jenkins, 2008). Reminiscing her whole experience with autism, Lana recognises the changes in her social identity throughout the years after the diagnosis of her son’s autism. Through narration, the use of a metaphor creates

powerful imagery of the threat autism had on her social identity. Rocque's (2010) research on mothers with an autistic child found the label of a diagnosis on their child posed a risk to their own social identity as a mother. The formation of a new identity was difficult for the mothers, however research suggests as mothers learn to adapt their primary focus moves onto their children (Rocque, 2010). Anita demonstrates this in the following quote.

**“It was hard to accept the changes in my life, but I like who I am now and my son is my world now...” (Anita, lines 88-90).**

### **Stress: Behaviour and Development. Behaviour**

**“When we go out and he gets angry and starts hitting me, I can't handle the stress, I always used to feel anxious to take him out, and I still do sometimes...” (Rebecca, lines 510-515).**

After the diagnosis of autism, although the mothers were aware of what was happening in their world, a new challenge emerged when coping with stress. The severity of behavioural problems in autistic children increase the stress levels in their mothers who are more likely to have a more pessimistic approach (Lyons et al, 2010). Due to the stress associated with behavioural problems, mothers like Rebecca who have recently had an autism diagnosis, are more likely to avoid situation where problems can occur. The diagnosis of autism is the main cause of stress, and additional problems such as behaviour can affect the mother's wellbeing and deter her from integrating into society (Duarte, 2005).

However, not all mothers experience severe behavioural problems. Naomi's experiences with behaviour have not been as excessive compared to the other mothers.

**“I'm lucky, he doesn't act very violent towards me, I'm not that depressed anymore because...” (Naomi, lines 300-305).**

It was interesting to hear a story of autism experiences that did not have an issue regarding behaviour. Naomi had less experience with violent behaviour with her son and in turn, it has had a positive effect on her wellbeing which decreases the risk on stress. Beer et al (2013) support this as mothers who reported lower levels of stress reported less behavioural issues in their children.

### **Development**

**“I know he's nearly three, and I know he's still got time but the fact he can't speak hurts me the most...” (Rebecca, lines 580-581).**

Behavioural issues are one of the most common challenges mothers face with a child on the autism spectrum, however during the interview process the mothers expressed their concerns in terms of their child's development. Rebecca's sombre tone when describing her wishes for her son to speak his first word emphasises her sorrow for the slow development associated with autism. Benson et al (2011) and

Davis (2008) both highlight the link between maternal stress and a lack of social development in their autistic children. The mothers experience stress, as they are concerned about whether their child will reach their potential social development to be able to fit in to the social norms.

## **Moving Forward: Support and Drive to Acceptance**

### **Moving Forward**

**“I was a lot weaker before, I couldn’t handle autism in my life, now it’s normal to me, it doesn’t upset me like it used to when he was first diagnosed...”  
(Naomi, lines 402-406)**

It was inspiring to listen to the mothers when they retold their journey from pre diagnosis to the present. When speaking of initial experiences with autism, the mothers spoke about their weaknesses and embraced their personal growth as a mother. After familiarisation of autism, mothers are positive about the future of their parenting and their child (Lutz, 2012). Zhang et al (2015) studied posttraumatic growth in parents and found social support encouraged acceptance for autism. Anita uses imagery to portray her journey to growth as a challenging yet exciting in the quote below.

**“it’s constantly up and down like a rollercoaster, but with the help of everyone around me I embrace that because the up’s with my son are my greatest memories...” (Anita, lines 499-504)**

**“Difficult, stressful (laughs) erm to be honest I wouldn’t wish it on my worst enemy...” (Rebecca, lines 519-521).**

When moving forward, Rebecca’s views differ from the other mothers, as her experiences of autism are recent therefore, she does not identify with the other mothers in acceptance. The use of laughter when describing her struggle with the diagnosis can be portrayed as a coping strategy. Although she is feeling the first stages of the other mother’s experiences, her motivation of moving forward and thirst for knowledge is inspiring, as she described her enthusiasm after the interview.

### **Support**

**“I’m grateful for my family, without them I don’t think I could have coped, whenever I need a break or help my sisters are the first people I call...”  
(Rachel, lines 480-482)**

Support was paramount for all the mothers as initially they felt there was a lack of support available for them. Family support encourages optimism in mothers leading to positive maternal outcomes (Ekas et al, 2010). Rachel’s reason for coping with the stigma and challenges having a child with autism are dedicated to the support of her family.

Support from healthcare professions and other mothers with autistic children are the key driving forces for the mothers' inclusion back into society (Weiss et al, 2013). Both Lana and Anita below support these.

**“The sessions really helped me a lot, it made me aware that it’s ok to get help and training on autism, after all not many people can cope very easy at the beginning” (Lana, lines 300-308).**

**“My friendship with these mothers are stronger than any other friendship I have, when our kids get together autism is just normal with us...” (Anita, line 400-408)**

The inclusion in training sessions where the mothers were able to network with other parents of autistic children which encouraged the mothers to socialise more and put less of a strain on their social identity. Support groups are essential as they can increase wellbeing and quality of life in mothers (Chiang, 2014; Cascio, 2012; Diken, 2013). The mothers have become active members within their own group of mothers socially constructing their own happiness and acceptance through support.

### **Drive to acceptance**

Positive perceptions of autism and their role as a primary caregiver enables the drive to acceptance of the disorder. Spending more time with their children generated a more positive outlook on life with autism and decreased stress levels (Kayfitz et al, 2012; Shu 2009). Anita and Naomi illustrate this below.

**“If I take autism away it will take his cuteness away...” (Anita, lines 506-510)**  
**“I love my son, I love his autism, I love everything about him...” (Naomi, lines 400-401).**

### **Conclusion**

Overall, the narrative analysis suggests that mothers also embark on a complex and challenging behaviour as well as the child with autism. Pre diagnosis years and the first year after diagnosis were identified as the most difficult when mothers were faced with isolation from society due to the social constructionism and stigma surrounding a mother's role on autism. However, as most research focus on the stress mothers experience, this analysis has found mothers do move towards acceptance and remain a strong close bond with their children.

### **Critical evaluation and future research**

The mothers who took part in this study all had a son with autism, which could have positioned the narratives in a certain way, for future research, involving mothers with daughter who have autism may demonstrate a difference in experience.

Furthermore, Fathers are unrepresented in studies of parenting a child with a developmental disorder, including a male sample of caregiver can enhance the quality of narratives.

The use of semi structured questions generated a vast amount of research, however being independently interviewed may cause nerves, using another qualitative design such as introducing focus groups with mothers may generate further empirical narratives.

The Mothers all experienced struggle and faced isolation throughout their journey, this research can be informative and helpful to parents with children who have recently been diagnosed with ASD.

### **Reflexivity**

Reflexivity in research is essential when understanding the nature of the research that was conducted (Finlay and Gough, 2003). My position as a volunteer with a charity for autism and mothers initiated my interest in conducting this research. I was also interested in other mother's experiences with autism due to a personal relation with someone who has a child on the autism spectrum. During the interview processes, I felt very inspired by the stories the mothers had shared, as I was more aware of the challenges and isolation they faced from society.

I am keen for improvements in the diagnosis process as most mothers shared their dissatisfaction of the time it takes for diagnosis.



## **Acknowledgements**

I would like to thank Dr Jo Ashby for her continued support, supervision and knowledge throughout the course of this research. I extend my gratitude to the five mothers for sharing their experiences and taking part in this research.

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