



'My greatest joy and my greatest heartache': A narrative analysis exploring mother's experiences of having a child on the Autism Spectrum

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### ABSTRACT

This research looks into how autism may affect, not only the child diagnosed with the disorder, but also the mother of that child. Previous research tends to focus on medical or genetic explanations of autism, or even the barriers faced by those with the disorder (Schall & McDonough, 2010), however this qualitative study moves away from the medical model to understand how autism impacts those around the child with the diagnosis.

To explore the accounts and experiences of what it is like raising a child with autism, six mothers were interviewed. Semi-structured interviews followed a loosely directed interview guide, derived from previous literature.

Using Emerson's (2004) six stage process for narrative analysis, four core topics dominated the interviews: years in the wilderness; total isolation; stress and partial resolution. Sub-themes were derived from these. The overall analysis suggests that the dominant model of living with autism (frustrating, negative and linked to 'suffering') actually did conceptualise reality for the women interviewed.

KEY WORDS:	EMERSON	AUTISM	MOTHER	SEMI-STRUCTURED INTERVIEWS	NARRATIVE ANALYSIS
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## Introduction

### Background to the research Project

There is a gap in the autism literature; little research exists that looks at how autism may impact the person with the disorder, as well as their family; this study aims to bridge that gap. According to Barnes (2002), disability is not only difficult to define but it can present challenges for society. Carnaby (2011) states that the impact of a singular case of autism may be quite diffuse, with carers often experiencing negative attitudes. This research is important as it aims to complement existing research based around disability in general, and then delve deeper into the phenomenology of autism.

### History of autism

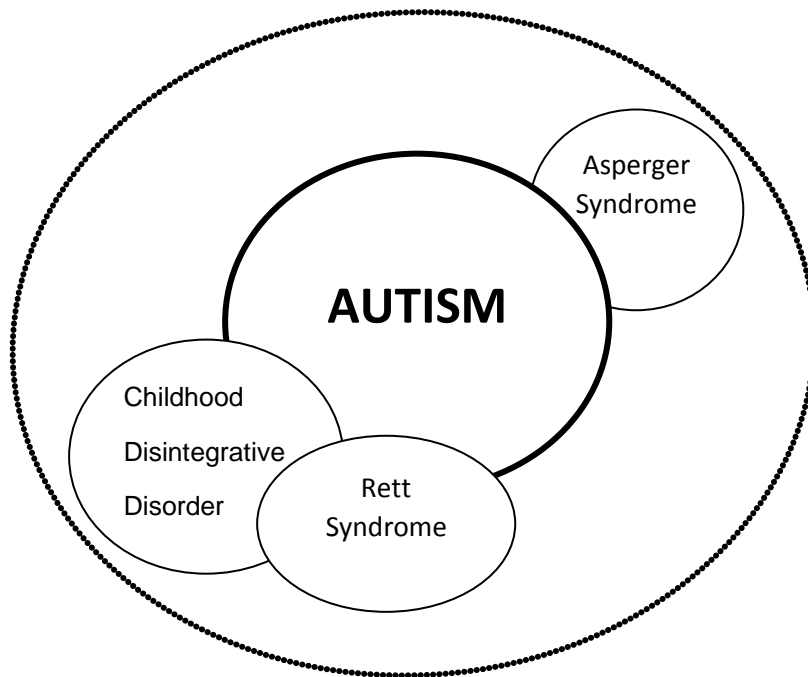
***“You know I had to fight for everything for him and back then it was harder because it was such a hidden disorder” (Samantha, lines 155-158)***

Autism was first mentioned By Bleuler in 1911, when trying to discuss and analyse the very specific behaviours associated with schizophrenia and according to Schreibman (1988) autism at this time was considered to be a rare condition linked mainly to males. However statistics show an annual rise in the diagnosis of autism spectrum disorder – in the year 2010 1 in 110 children were diagnosed with autism and in the year 2012 1 in 88 children were diagnosed with autism (Patel, 2012). Autism spectrum disorder is recognised in the DSM-IV it defines autism as ‘persistent difficulties in social communication and social interaction’. Stemming from this the DSM-IV also suggest two sub-domains that facilitate a diagnosis of ASD: 1. Social communication/interaction 2. Restricted repetitive behaviours.

When originally conceptualised autism was the chosen nomenclature, but Autistic ‘Spectrum’ is now more commonly used (Potter, 2002). However which disorders should be included in the spectrum and how broadly this spectrum should extend does still remain controversial (Robertson & Derrick, 1998).

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**Figure 1** maps out how psychologists have tried to explain the Autistic 'Spectrum'.



**Figure 1:** Outlines the association among autistic spectrum disorders. The overlapping circles show how the symptoms overlap although the disorders do not. Autism appears in the centre and is classified as the prototypical disorder as its symptoms and related domains are most severe.

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## Aetiology and characteristics of autism

***“But when I look back it definitely wasn’t the MMR jab Tom was born with autism” (Samantha, lines 142-144)***

The aetiology of ASD remains unknown (Mesibov, 1997); because of this, diagnosis is defined through observation and a check for behavioural abnormalities. According to Muhle (2004), autism is one of the most complex neurobiological disorders, however there is still insufficient evidence to firmly say that the disorder derives from biological/genetic factors (Skafidas & Testa, 2012) and therefore no single cause can be defined. Researchers La Salle & Mitchell (2013) argue this further stating that ASD is probably linked to both multiple genetic and environmental factors and therefore play a key role in the aetiology of the disorder. According to Smith & Mulick (2004) ASD can be characterised by the following core symptoms: echolalia (repeating words and phrases); mannerisms (hand flapping or walking on tip toes) and social interaction difficulties.

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## Mothers, stress and ASD

***“This is going to sound horrible but I felt embarrassed. I didn’t want an odd son. I just wanted him to be normal” (Maria, lines 177-180)***

Whilst qualitatively exploring the lives of 12 West midlands families, all of which had children with ASD, Read (2000), reported that in the majority of the households the mothers were the primary carers. Read (2000) showed that, although some of the marriages appeared to be strengthened by having a child with ASD, there was also a stronger likelihood of relationship breakdown, with mothers in particular becoming lone parents. Even though Read confirmed what researchers of autism might intuitively expect to find, there remains a key issue around relationships that needs examining.

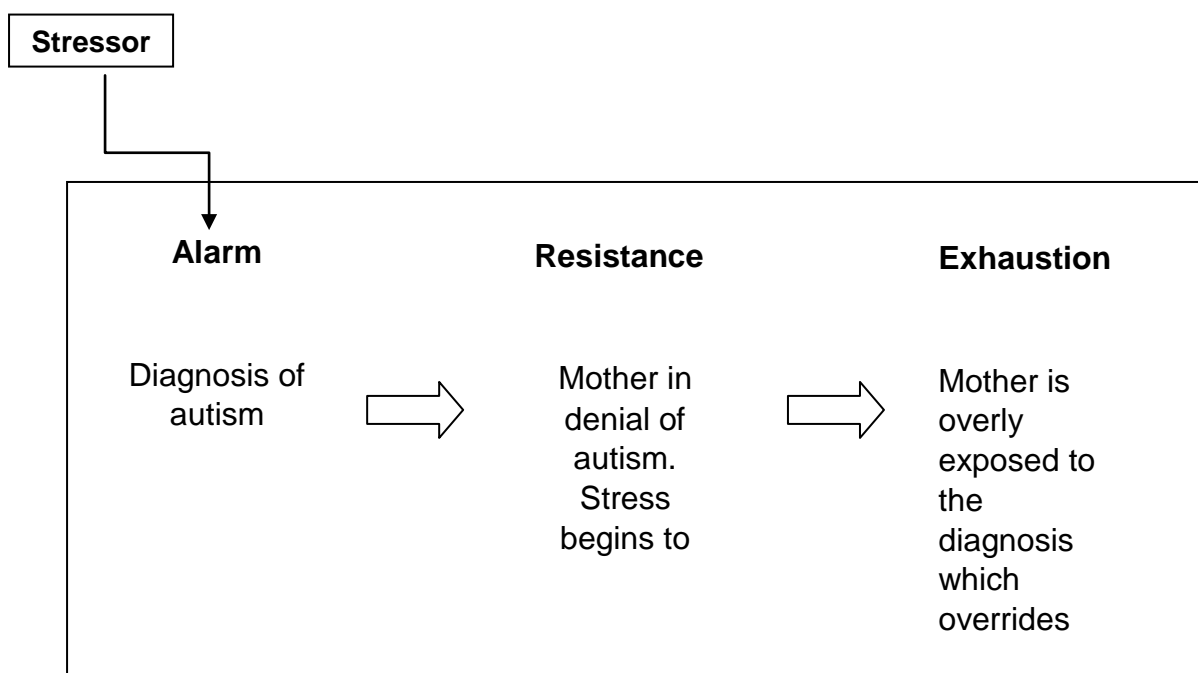
Research conducted by Olsson et al (2001) used the Beck Depression Inventory (BDI) to assess levels of depression in mothers of ASD children versus mothers of children without ASD. Mothers with children with autism had higher depression scores (mean = 11.8) than mothers of children without autism (mean = 9.2). Bromley et al (2004) took this study further by adopting a more qualitative methodological framework this allowed researchers to reveal that many mothers with children with ASD often refer to daily living as tiring, time consuming and frustrating.

When a child is diagnosed with autism, their siblings, parents and family friends may feel as though they live in a completely separate, somewhat incompatible world (Mac Donald, 2003), and according to Moes & Koegel (1992) this is one of the main reasons why mothers with children on the autism spectrum experience stress. The term ‘stress’ is an issue that is embedded within society but can also mean many things to different people Ogden (2012). For many years researchers have struggled with defining stress (Bartlett, 1998), however psychologists tend to define stress as an event that contributes to biochemical, physiological, behavioural and psychological changes within an individual (Cohen, 2012).

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Davis & Carter (2008) were able to provide empirical evidence that mothers of children with autism were more vulnerable and susceptible to stress immediately following a diagnosis of autism. The mothers studied reported that the diagnosis exposed them to the challenges and difficulties that they might have to face as the child grows up. In 1956 the Selye general adaption syndrome was developed and fully outlines three stages in the stress process. This theory cannot only be applied to the research carried out by Davis & Carter (2008) but can also provide evidence for this current research project by revealing that mothers soon after a diagnosis of autism can be impacted by stress. Even though the Selye (1956) stress theory is dated it has specifically been chosen to be used within this current piece of research because it offers a clear step by step process in how situational factors (stressors) can influence the stress response within individuals.

**Figure 2** Outlines how the diagnosis of autism can influence stress within mothers.



## Reaction and coping after the diagnosis

***“Part of me wanted to come outside of the hospital and throw myself under a train”*** (Anne, lines 126-128)

When an individual is made aware that they are going to become a parent, automatic instincts leads the individual to imagine a life picture for this new person that will be a part of their lives (Barson & Roth, 2010). However, when at the start of this new life the parent is exposed to numerous types of unusual behaviour, lack of affective contact, severe developmental delay and strained communication difficulties the original picture formed is challenged and in most situations completely fragmented (Prizant, 2000).

According to Mansell and Morris (2004) soon after the initial diagnosis of autism mothers in particular reported a diverse range of negative emotions and an interesting finding was that mothers felt that their identity would have to change. From the evidence Mansell and Morris (2004) were able to conclude that in many cases the reaction to the diagnosis of autism was negative and mothers in particular were more likely to be affected. Sigán & Barker (2010) were able to provide further evidence that the diagnosis of autism not only impacted on individual members of the family but could also have an effect on the family unit as a whole as parents with children on the autism spectrum were almost twice as likely to divorce compared to couples without children on the autism spectrum.

Despite all the negative findings cited above, there is still some evidence that many families benefit from raising a child with autism (Walsh, 2003). The experience of consistently caring for the child can make people stronger; in this context, caring may lead to ‘resilience’ (Altiere, 2009). Lin (2008) defines ‘resilience’ as the ability to withstand hardship, which in turn develops into becoming stronger and more resourceful. According to Lee (2009) young mothers in particular reported that soon after the diagnosis of autism they developed ‘heightened patience’; this was the main mechanism that helped them cope with their child’s disruptive behaviour.

Research rarely claims that people cope easily with autism, its symptoms, or the challenging behaviours associated with it (Aarons & Gittens, 1992). Tway (2007) suggested that some families may use negative coping mechanisms to respond to disruptive behaviours: e.g. ‘Escape and Avoidance’. This is where they either escape, or completely avoid everyday settings (e.g. a supermarket), as these environments might exacerbate autistic difficulties. Later research by Tway (2008) revealed that this ‘escape-avoidance’ mechanism increased feelings of depression and isolation within both parents of the child.

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## **Method**

### **Method Rationale**

**‘The search for method becomes one of the most important problems of the entire enterprise of understanding the uniquely human forms of psychological activity. In this case, the method is simultaneously prerequisite and product the tool and the result of the study’**

(Vygotsky in Newman & Holzman, 1993 p32)

### **Objectives**

1. To interview six mothers of children with autism, to explicate whether a diagnosis impacts on all or any of those who surround the children.
  2. To explore further how each mother manages daily living with her child, particularly asking about coping strategies and ways to manage any disruptive behaviour.
  3. To ask the 6 mothers involved in this study whether caring for a child with autism is experienced as stressful, motivational, and rewarding or if they would describe it differently
  4. To look at how mothers of children with autism perceive themselves and their social identity following diagnosis.
  5. And ultimately to give mothers raising a child with autism a ‘Voice’.
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## **Philosophical background**

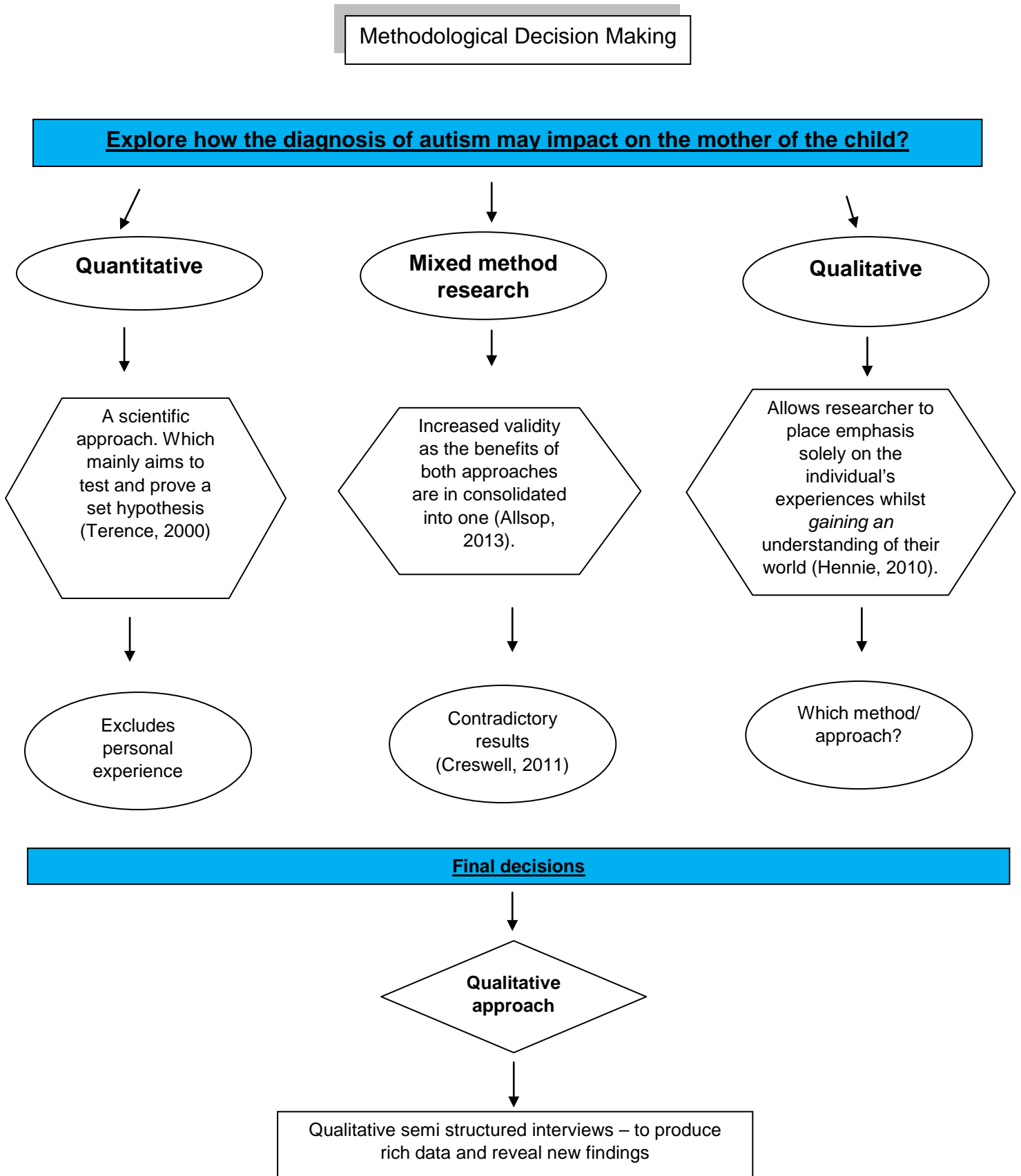
Lincoln & Guba (1985:15) regard 'qualitative' research as a paradigm with a worldwide view, 'a way of breaking down the complexity of the real world', this is why this study employed the qualitative approach as the design. Weinberg (2002) states that the use of quantitative methods averts the researcher from exploring the 'truth' about the participants and inhibits them from accessing rich detail. Marks (2000) argues this further by stating that qualitative method allows for deep exploration whilst gaining the core significance of the topic being researched.

## **Methods and decisions**

The controversy built around researching autism has made it extremely difficult for researchers to select the appropriate form of methodology (Brock & Jarrold, 2004). The lack of coherence in applying definitive theoretical principles and theories has meant that researchers have often produced contradictory results (Southgate, 2008). According to Dingwall et al (2013) the foundations on which qualitative researchers work are their ontological and epistemological positions and these stances are pivotal to any qualitative research as they shape the decisions made about the method. The previous statement combined with the researchers epistemological positioning and current profession as a senior special educational needs support worker was one of the major influences to operate under a qualitative analysis.

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**Figure 3** 'Methodological decision making' diagram illustrating a visual representation of how both the method and design were selected.



## **Participants and participant recruitment**

**‘Even when they are given clearly presented guidelines, it is unlikely that interviewees will have been in a similar situation before, one which the focus is on them for a considerable period of time, with the expectation that they should ‘tell their story’ in depth’**

(Estelle King, in Richardson 1997, p177)

5 mothers who have a child with autism were interviewed for this study. The women comprised of an opportunity sample recruited from the following autism related charities: ‘The Together Trust’ and ‘Hillingdon Autistic Care and Support Centre’. Each interviewee was given an invitation letter (see appendix 1), along with a consent form (see appendix 2) and an interview schedule (see appendix 3).

See appendix 4 for descriptive cameo sketches for each participant.

## **Data collection method**

According to Hodges (2006) the use of semi-structured interview not only puts emphasis on the researcher to keep some control over the study but also allows the researcher to go straight in and explore relevant research topics. This is one of the key reasons why this current piece of research used semi-structured interviews to gather data.

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## **Interview process**

**'Interviewers must decide how to present themselves and their project, and this will be influenced by who is being interviewed and where'**

(Reinharz, in Richardson 1997, p177)

Individual 1 hour face-to-face interviews were carried on each of the 6 participants and each was recorded (with full consent). Once participants confirmed their participation, an interview environment was selected this was employed so that each participant could freely discuss the topics they chose not only in an environment that was familiar to them but somewhere they felt most comfortable. At the end of the interview the interviewee was debriefed the researcher provided the participant with relevant information if they needed further counselling or support with the topics they discussed. Physical environment, recording and building rapport were all considered by the researcher prior to the interviews and according to Greenaway (2000) they are vital elements of the semi-structured interview data collection method.

### **Physical environment**

The researcher ensured that the setting where the interviews took place was welcoming and comfortable more importantly a location that was chosen by the interviewee, according to Lindlof (2011) a familiar surrounding puts the interviewee at ease and leads to psychological comfort.

### **Recording**

Opdenakker (2006) states that recording equipment usually will have different meanings to different interviewees, for some it may evoke feelings of suspicion or hostility while others may see it as a sign of serious nature to the project. The researcher clearly explained that all tapes would be stored in a secure place where only the researcher would have access to and that all transcripts would be anonymised as pseudo names would be used throughout the interview and throughout the entire research project.

### **Building Rapport**

Building rapport with each individual interviewee is a key ingredient not only for successful qualitative interviewing but to create a successful research project (Steinar, 1996). The researcher had a personal positive relationship with each interviewee and therefore the 'positive rapport' (King & Horrocks, 2010) stemmed from each interview.

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## Data analysis method

Upon completion each interview was individually transcribed ready for the researcher to conduct a narrative analysis on the data. Narrative analysis was selected primarily due to the elasticity it requires across epistemological approaches. The researcher was keen to adopt an analysis method that involved considerable interpretation and involvement. According to Emerson (2004) a narrative analysis allows the researcher to extract postulating theories, underlying ideas and conceptualisations closely interrelated to the research question. Howitt & Cramer (2011) state that a narrative analysis goes beyond counting explicit words or phrases instead it allows the researcher to solely focus on implicit and explicit ideas. Fraser (2004) provided 6 structural levels of narrative interpretation that should be employed by researchers when conducting a narrative analysis and the table below illustrates these levels.

**Table 1** Structural levels of narrative analysis

<b>Stage 1</b>	Read and re-read the interview transcript to grasp the content.
<b>Stage 2</b>	Delete all the interviewer questions and comments from the transcript.
<b>Stage 3</b>	Read transcript again
<b>Stage 4</b>	Begin to describe line by line what is being said – avoid making interpretations at this stage.
<b>Stage 5</b>	Begin to identify prominent topics from within the transcript.
<b>Stage 6</b>	Once stage 1-5 have been conducted on each individual transcript. Bring all the transcripts together and carefully identify re-occurring topics across all the interview transcripts to create one coherent story which outlines the experiences of all interviewees.

An example of how the narrative analysis was conducted can be found in appendix 5.

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## Ethical considerations

Ethics refer to honourable principles and rules of conduct (Wadeley, 1991) and any piece of psychological research involving human participants automatically involves ethical issues (Folkman, 2000). This piece of research followed the 'Codes of Ethics and Conduct' according to the British Psychology Society (2009:10). To ensure that this research project was 'suitable' the following ethical considerations were formalised:

- ✚ The researcher's personal agenda will be repeatedly stated to all participants.
- ✚ Legal and mental ability from the participants will be ensured by the researcher first before participants can give full consent.
- ✚ Participants will be made aware that total confidentiality will not be possible to maintain as direct quote from their interviews will be used in the final report – however the researcher will assure that their contributions are kept anonymous, all names will be alter to protect anonymity.
- ✚ Each participant will take part in the research voluntarily without coercion (Forshaw, 2004).
- ✚ During the research project the researcher will be using her own forename at all times to reduce formality and to put participants at ease.
- ✚ The researcher will make all participants fully aware that they are able and have the right to withdraw from the research at any stage without penalty.

The full completed application for the ethics approval form can be found in appendix 6.

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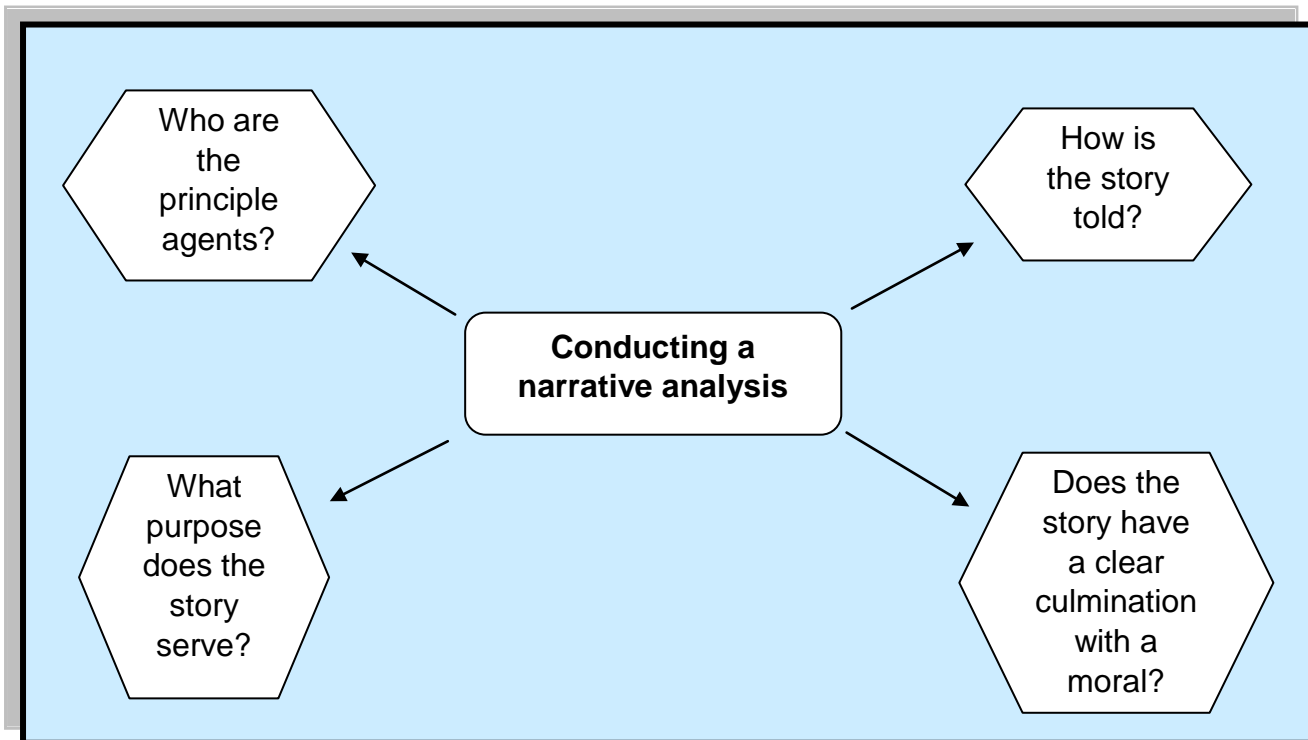
## Results and analysis

According to Holstein (2012), narrative analysis asks the researcher to use inductive reasoning to look for recurring topics across the dataset. Recalling our personal lived experiences is something that is quite intrinsic to whom we are as humans (Silverman, 2006). Personal retrospective accounts of past experiences which are gathered through a sequence of amorphous conversations between a researcher and the story teller/participant is how Brophy (2009) outlines narrative analysis. Taylor (2013) labels narratives as collective products that are produced by people in the context of specific historical, social and cultural locations. However the key element that separates narrative analysis from other qualitative approaches is the notion that a narrative portrays characters and their actions in imagery form which illustrates how the individuals interpret their own world. The visual representation below illustrates the questions considered before conducting the narrative analysis.

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**Figure 4** A visual representation outlining the key questions that could produce a successful narrative analysis.

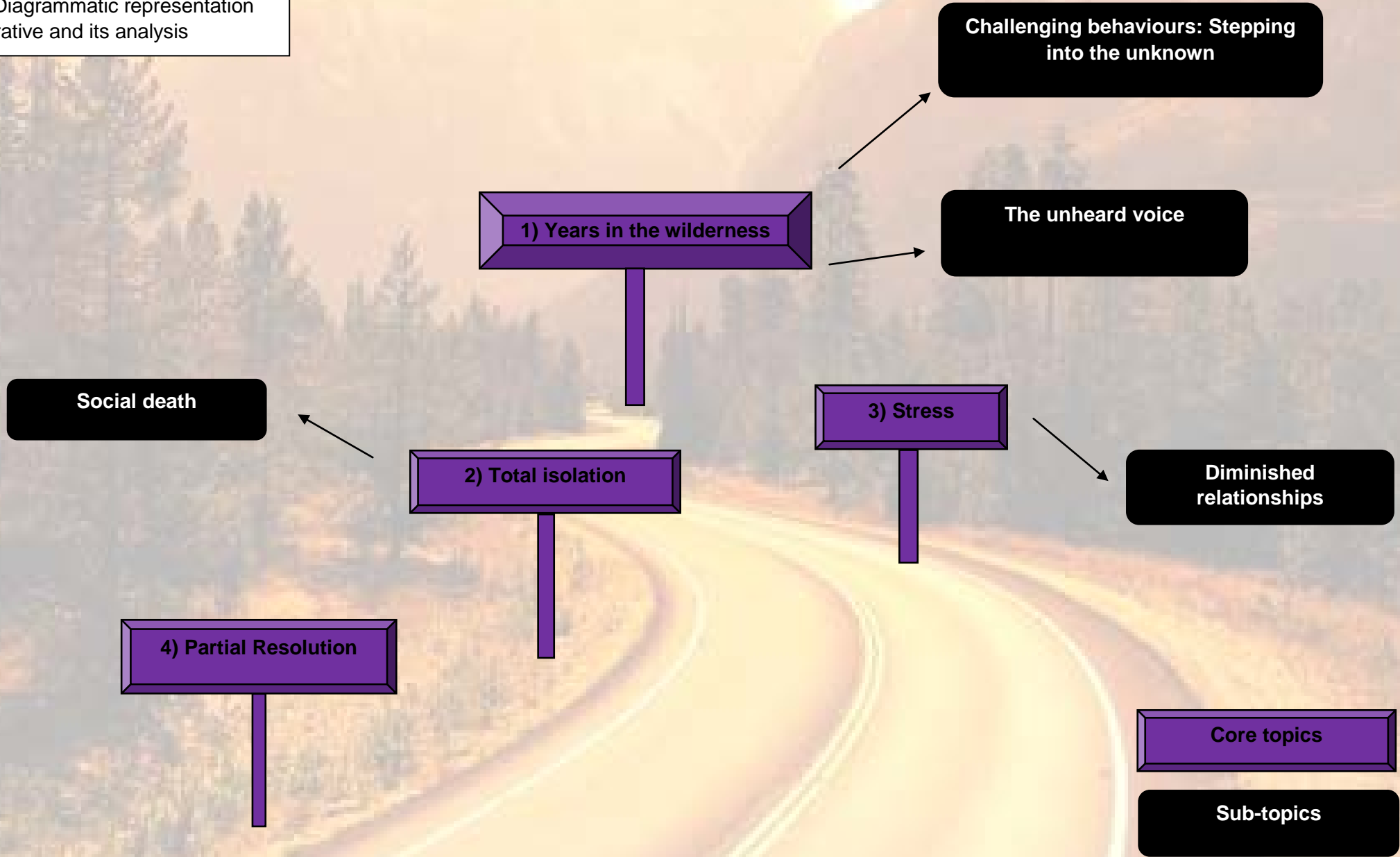


After careful consideration and frequent comparison, similarities across the interview transcripts were highlighted and unanticipated insights gained. Using narrative analysis meant that a phenomenological approach could be used to reveal peoples 'lived experiences', where emphasis was on attempting to fully understand the individual, highly personalised stories of each of the participants. As the accounts given by mothers of children with autism were central to this study, the four topics chosen for focus were those which seemed to dominate the entire dataset (see below):

1. Years in the wilderness
2. Total isolation
3. Stress
4. Partial resolution

After further analysis each topic was broken down and 'sub-topics' were carefully identified and shaped. Both the core and the sub-topics are illustrated below with an analysis map.

**Figure 5** Diagrammatic representation of the narrative and its analysis



## **Narrative analysis and discussion**

All five interviews took place in a location chosen by each mother; each preferred their own home, when the children were at school. This was possibly to: minimise any distractions, attenuate the pressure of the recording device; possibly so that they might more fully immerse themselves in the past; and also so they could revisit their own lived experiences raising and supporting a child with autism. According to Brinkmann (2013), when participants are given the opportunity to decide where they want to share their story with the researcher, they are not only made more comfortable with the research process, but they are automatically put at the forefront of the entire project.

The interviews started with questions about life pre-diagnosis; this meant that very early on, the first core topic emerged:

### **Years in the wilderness**

It was quite alarming that for all the mothers there was an extended period of time where they were unable to explain their child's idiosyncratic behaviour. This is something that is illustrated through the words of Jane below:

***“I did start to notice that things were extremely different with my daughter....we just knew there was something different about her, and this was for a nine year period”*** (Jane, lines 33-40)

The not knowing stage is a phrase used by Osborne (2008) and according to Osborne (2008) this is a difficult time for parents daily living becomes a challenge and parents begin to realise that their child's peculiar behaviours are not accepted by others. This is something that Anne could closely relate to:

***“For me it was the not knowing; that was difficult how could I integrate myself into the world when my child was not accepted?”*** (Anne, lines 52-56)

In comparison Gray (2002) also acknowledges that the not knowing stage is the hardest for parents however Gary (2002) reports that this period can often leave parents feeling frustrated, confused and at times embarrassed and subsequently these emotions lead to a reduction in confidence. This is a process that Jane experienced:

***“And eventually I suppose, confidence in parenting was reduced for me” (Anne, lines 160-163)***

‘Challenging behaviours: stepping into the unknown’ and ‘the unheard voice’ have been highlighted as sub-topics. Persistence in seeking advice and trying to be heard by numerous health care professionals appeared to be a demanding experience. Mothers during this period experienced a wide range of emotions and this is something that Maria could relate to:

***“I was just angry and hurt because I had been fighting for years with the psychologists and doctors and they just didn’t listen, I always knew there was something wrong with him” (Maria, Lines 75-79)***

## Challenging behaviours: stepping in the unknown

***“He would cry a lot, like excessive amounts, you know for hours...and he would reflux a lot”*** (Samantha M5 77-79)

***“He would reflux a lot ... so I had sheets all over the floor, and he would always be refluxing bits of milk”*** (Anne M1 29-32)

Excessive refluxing is an early sign of autism that mothers often recall once their child is older and various other signs and symptoms are brought to the surface (Ozonoff, 2010). Besides the early signs of autism the mothers were keen to reflect on the more demanding challenging characteristics as demonstrated by Anne and Maria below:

***“I think the hardest things were the peculiar things he used to do like kick holes in the doors; every door in the house”*** (Anne lines 313-315)

***“He would completely turn, smash the whole of the bedroom, telly, laptop, everything in the house would be ruined; this could last for 12 hours”*** (Maria lines 283-293)

According to Matson & Wilkins (2008), parents find the challenging behaviours the hardest to cope with; they have major impacts on how they live their lives, as can be seen in Maria’s words below:

***“His behaviour was horrendous; I could not take him anywhere at all, and I am serious”*** (Maria M1 53-56)

It is very clear that the mothers were being presented with all the symptoms of autism which were impacting on their daily lives but were still left not knowing the cause behind the behaviour.

## The unheard voice

According to Ginny & Norwich (2012), being left ignorant by health care professionals left parents feeling as though they were invisible, as Maria says below:

***“I was still very hurt and upset because no one was listening to me you know the doctors, nurses, psychologists, the specialist just did not listen to me”***  
*(Maria, lines 74-84)*

Anne also says that she experienced this and states:

***“You just think that they don’t believe you, and you think, they think you just making a fuss”*** *(Anne, lines 96-99)*

Equally Samantha shared the same experiences as Anne and Maria:

***“I did speak to the health professionals about my concerns, but they all say the same things, you know, don’t worry about it, you’re doing everything that you should be doing, you know, boys take longer to develop, and all the rest of it, you know, it was very frustrating”*** *(Samantha, lines 108-113)*

When mothers are consistently shut down by doctors about their child’s delayed development, and their distinctive behaviour problems, they often feel as though their concerns are being minimised, or even ignored (Goin-Kochel et al, 2006).

## Total isolation

Once a mother is given that firm diagnosis, the autism becomes their life and eventually they are pushed further away from the norms of society and find it extremely difficult to move away from their rigid and controlled life style and this can produce feelings of extreme loneliness (Woodgate et al, 2008). The responses made by Suzanne and Maria illustrate the second core topic – total isolation:

***“I was completely lost felt alone and consistently isolated”*** (Suzanne, lines 404-406)

***“I was totally alone so if I did use extreme things to cope then it was because I didn’t have an alternative”*** (Maria, lines 349-353)

It was at this stage that mothers were truly exposed to a trapped life so much so that they were actually living it and asking them to re-live these experiences did evoke some distress. Many would think that once these mothers were given the diagnosis they could begin to enjoy their life and their child because they had been given what they had been fighting for, for many years however the diagnosis only seemed to lead to extreme isolation which impacted on their quality of life and this is something Anne experienced:

***“People don’t realise you can’t keep in contact with your own family that’s how bad things can get”*** (Anne, lines 376-378)

This was something Samantha also experienced:

***“None of my family wanted him because they thought he was horrendous so I NEVER had a break!”*** (Samantha, lines 288-291)

## Social death

Many mothers raising a child with autism will often avoid everyday external situations like being out in the community or participating in parent-child social activities as this can create immense fear and anxiety purely because of the unpleasant reactions they receive from others (Lord & Edwin, 2013). It's almost as though the 'autism' forces them into an undesirable category which is not accepted by society so it becomes extremely difficult for mothers to immerse themselves around those who have not been impacted by their situation (Thomas, 2002). Inevitably their social life decreases and this is illustrated within the sub-topic social death and is something that has been experienced by Maria:

***“When I took him out and about, I mean the way they are, you know impulsive, he would generally kick off - people use to look, and just thought he was a naughty child, you know, they would make horrible comments without knowing that actually he has autism” (Maria, line 425-434)***

Equally the reduction in participating in everyday social activities was also experienced by Samantha:

***“You see most would say well I would have an evening off to myself you know go out with my friends have a glass of wine but of course because I was a single parent that was all a dream to me” (Samantha, line 282-287)***

According to Meirsschaut et al (2010) when parents experience unpleasant responses from members of society this can often lead mothers avoiding the norms of everyday living. This is demonstrated by the words of Anne, Suzanne and Jane:

***“It was terrible, awful I mean I stopped going in supermarkets because he couldn't cope, I stopped going for about 13 years” (Anne, line 333-337)***

***“I remember, over the Christmas period for 3 whole days we didn't even go out, I didn't even unlock the front door” (Suzanne, line 483-485)***

***“So there was a point when we were just like okay so yeah we are not going to go out, we are just going to stay indoors” (Jane, line 524-526)***



## Stress

Families of children with autism often report high levels of stress and this is said to be a normal part of a family's journey with autism (Dabrowska & Pisula, 2010). According to Boyd (2002) it's normal for parents to feel a range of emotions they may feel shock, sadness, anger, denial and loneliness and these feelings are not only sources of stress but are stages in the grieving process which parents of a child with special needs will often go through after getting a diagnosis. This is something Suzanne illustrated through her words:

***“It took me a long time to come to terms with it, almost like a grieving process and that's when the stress started for me really”*** (Suzanne, lines 116-120)

Mothers often report feeling more stressed than fathers, possibly because mothers tend to be the primary caregivers within a family unit (Estes, 2009). Both Jane and Maria discuss their experiences of stress:

***“I think you could say that I was losing control and wanted some attention and at this time, I was constantly thinking I can't do everything.....I went to the doctors and sat there and just cried, I was just so stressed out with everything”*** (Jane, lines 475-485)

***“There was a period of time where I always felt down, you know, nothing made me happy life and living with autism was just a struggle”*** (Maria, lines 212-216)

Research shows that families with children with autism report that having trouble handling their child's challenging behaviour and unpredictable sleeping patterns is the main reasons why they become so stressed (Pisula, 2010). These are issues that both Samantha and Suzanne could relate to:

***“I just wanted to give up, (begins to get upset) you know, I just couldn't see a way out of it I was just so alone, his behaviour was just awful”*** (Samantha, lines 135-139)

***“Some nights, I would just sit there and cry my eyes out and just think why you know, when he wouldn't sleep or when his behaviour was difficult”*** (Suzanne, lines 288-290)

## Diminished relationships

The pressures of having a child that does not adhere to norms of society makes coming to terms with a diagnosis that much harder and instead of couples empowering one another they tend to distance themselves and this is when their relationship becomes non-existent (Freedman, 2012) and this was something Suzanne and Samantha experienced:

***“Our relationship went from being rocky to non-existent in a very short period of time within two three weeks of the diagnosis it was over”*** (Suzanne, lines 125-129)

***“Eventually we got the diagnosis at age 8 and soon after I was officially a single parent – he couldn’t cope”*** (Samantha, lines 132-135)

When parents eventually receive the autism diagnosis often parents don’t realise that raising a child with autism can affect their relationship so they tend to ignore their partnership and focus solely on the child (Waterhouse, 2013) subsequently their relationships break down. Luther et al (2005) states raising a child with autism can bring many positive changes to a relationship however it is more likely to bring new challenges and dealing with these challenges constructively can minimise the strains caused by disability, this could include participating in counselling and seeking professional advice. This is something that was illustrated through the words of Maria and Suzanne:

***“I mean I think unless parents get more help and more things explained to them it will affect relationships, it would have been great if we could have gone to some sort of therapy together, you know, maybe we would still be together (Laughs)”*** (Maria, lines 482-490)

***“You know there needs to be more professional help for parents so they are able to cope with it all otherwise your relationship disappears like mine did”*** (Suzanne, lines (703-708)

## Partial resolution

Although majority of mothers raising a child with autism face numerous challenges some mothers are still able to reflect on the positives, for example some report that they learn mortality, patience, compassion but more importantly respect for others (Kayfitz, 2010). Reflecting on the positives was something that all mothers were able to do and this essentially led them to persevere through the difficult periods:

***“The happiest memory I have with Tom is when he finally spoke that day conkers all the hard days”*** (Suzanne, lines 763-765)

***“Some of the days digging on the beach were the best days”*** (Anne, lines 870-872)

***“Deep down he is a warm loving person there is no doubt about that”*** (Maria, lines 571-573)

***“The happiest memory would be when he said his first word it came so late at the age of 5 but being told he may never speak when that day came I was over the moon the best day ever”*** (Samantha, lines 409-414)

## Reflexive Analysis

Supporting and in some sense caring for individuals of all ages with autism spectrum disorder for over 4 years provided the stimulus for me to become involved with an autism related piece of research. From the very early age of 17 I became fully committed to working alongside those impacted by a diagnosis of autism. I have been involved in offering one to one care for those with autism in personal home environments, educational services, hospital surroundings and in some instances travelling abroad to offer my services and primary expertise knowledge.

Once my research proposal had been approved I was keen to fully immerse myself into the mechanics of the study. This meant that I had to insure my chosen methodological framework suited my personal moral standpoints. I knew I wanted to choose a structure that allowed my participants to feel comfortable and at ease with sharing their stories. My main goal was to employ a framework where none of the participants held back, I wanted them to use the interview time to finally exercise their voice and share the challenges they have been faced with. According to Gelissen (2012) the method is not only created to suit the needs of the researcher the method should be structured and altered around the participants.

Personal reflexivity is a process that cannot be ignored by any qualitative researcher as it involves identifying your subjective interests in relation to the research project (Hunt & Sampson, 2006). Before I had even began to meticulously plan my piece of research, I had a vision that I wanted to remain imperceptible, I was adamant that my personal agenda would not cloud the presence of the mothers who in my eyes were at the forefront of this study. However I soon realised that my way of thinking was too simplistic and I eventually had to abandon my own personal ideology of remaining invisible – I was very much a part of the research process. Nonetheless this did not reduce the credibility of my research project in any form, I was still able to give all mothers a voice which had been a long time coming for all the mothers interviewed.

Very early on I knew I wanted to use the qualitative paradigm this is because I wanted to insure that the participant's experiences were of central focus to the findings which would have been impossible to achieve had I employed the quantitative approach. I knew that complete dedication would be required so that I could fully explore the research question. More importantly I was eager to produce a comprehensive story that truly conceptualised the lived experiences of all the mothers interviewed. Before I conducted my first interview I remember having a mixture of emotions part of me was excited as I finally had the opportunity to lead my own personal research project in an area that I am completely committed to. However I also felt quite anxious because I was taken out of my comfort zone – conducting an interview is not something that I do regularly. However I am now able to see that this is a useful skill that I can continue to use within professional practise. Subsequently soon after completing my second interview my initial feelings of anxiety somewhat diminished as I realised that for all of my participants I was the 'first' individual to allow them to re-tell their story.

### **Critical evaluation**

The main weakness of this study is the limiting sample, only six mothers were interviewed five of which were from a working class background, making it harder for the researcher to draw any generalised conclusions. The sample was also more susceptible to demand characteristics as five of the mothers had a personal relationship with the researcher. An additional weakness is the reliability of the diagnosis of the child with autism, all but one were diagnosed with severe autism therefore the mothers stories may not have been entirely representative of all children on the spectrum. The main strength of this study is that the interviews took place in a natural environment chosen by each of the mothers, adding to the ecological validity of the study.

### **Future research**

For future research it would interesting to explore how siblings within a family are also impacted by a diagnosis of autism. Equally it would also be interesting to see whether fathers are impacted in the same way as mothers.

## References

- Allsop, J. (2013) *Researching health: qualitative, quantitative and mixed methods*. 2<sup>nd</sup> ed., Los Angeles: Sage
- Altieri, M. (2009) Family Functioning and Coping Behaviors in Parents of Children with Autism. *Journal of family and child studies*, 18(1) pp. 83-92
- Aarons, M., Gittens, T. (1992) *The Autistic continuum: an assessment and intervention schedule for investigating the behaviours, skills and needs of children with autism or autistic spectrum difficulties*. Windsor: NFER-NELSON
- Barson, C., Roth, L. (2010) *The autism spectrum in the 21st century: exploring psychology, biology and practice*. London: Jessica Kingsley
- Bartlett, D. (1998) *Stress: perspectives and processes*. Buckingham: Open University
- Barnes, C. (2002) *Disability*. Oxford: Polity
- Boyd, B. (2002) 'Examining the relationship between stress and lack of social support in mothers of children with autism'. *Focus on Autism and Other Developmental Disabilities*, 17(4) pp 208-215
- Brinkmann, S. (2013) *Qualitative interviewing*. New York: Oxford University Press
- Brock, J., Jarrold, C. (2004) To match or not to match? Methodological issues in autism related research. *Journal of autism and developmental disorders*, 34 pp 81-86
- Bromley, J., Hare, D., Davison, K., & Emerson, E. (2004) 'Mothers supporting children with Autistic Spectrum Disorders'. *Autism*, 51(9) pp 702-714
- Brophy, P. (2009) *Narrative-based practise*. Aldershot: Ashgate
- Carnaby, S. (2011) *Learning disability today: the essential handbook for carers, service providers, support staff and families*. 3<sup>rd</sup> ed., Brighton: Pavilion Pub
- Clarke, V., Braun, V. (2008) Using thematic analysis in psychology. *Journal of Qualitative research*, 3(2) pp. 77-101
- Creswell, J. (2011) *Designing and conducting mixed methods research*. London: Sage
- Cohen, S. (2012) Who's Stressed? *Journal Social Psychology*, 42(6) pp. 1320-1334
- Coyle, A. (2007) *Analysing qualitative data in psychology*. London: Sage

- Dabrowska, A., Pisula, E. (2010) 'Parenting stress and coping styles in mothers and fathers of children with autism'. *Journal of Intellectual Disability Research*, 54(3) pp 266-280
- Davis, N., Carter, A. (2008) 'Parenting Stress in Mothers of Toddlers with Autism Spectrum Disorders: Associations with Child Characteristics'. *Journal of Autism and Developmental disorders*, 38(7) pp. 1278-1291
- Dingwall, R., De Vries, R., Bourgeault, L. (2013) *The Sage handbook of qualitative methods in health research*. Los Angeles: Sage
- Emerson, P. (2004) *Critical narrative analysis in Psychology: a guide to practise*. Basingstoke: Palgrave Macmillan
- Estes, A. (2009) 'Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay'. *Autism*, 13(4) pp 375-387
- Folkman, S. (2000) *Ethics in research with human participants*. London: American Psychological Association
- Forshaw, M. (2004) *Your undergraduate psychology project: a BPS guide*. Oxford BPS Blackwell
- Freedman, B. (2012) 'Relationship status among parents of children with autism spectrum disorders: a population-based study'. *Journal of autism and developmental disorders*, 42(4) pp 539-548
- Gelissen, J. (2012) *Qualitative research methods*. London: Sage
- Ginny, R., Norwich, B. (2012) 'Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders'. *Clinical child psychology and psychiatry*, 17(2) pp 229-245
- Goin-Kochel, R., Mackintosh, V., Myers, B. (2006) 'How many doctors does it take to make an autism spectrum diagnosis'. *Autism*, 10(5) pp 439-241
- Greenaway, P. (2000) *Interviews*. Jackson: University Press of Mississippi
- Hennie, B. (2010) *Analysis in qualitative research*. London: Sage
- Hodges, K. (2006) Structured Interviews. *Journal of Child Psychology*, 34 (1) pp. 49-68
- Holstein, J. (2012) *Varieties of narrative analysis*. Los Angeles: Sage
- Howitt, D., Cramer, D. (2011) *Introduction to research methods in Psychology*. Harlow: Prentice Hall
- Hunt, C., Sampson, F. (2006) *Writing: self and reflexivity*. Basingstoke: Palgrave McMillian

- Kayfitz, A. (2010) 'Positive experiences of mothers and fathers of children with autism'. *Journal of Applied Research in Intellectual Disabilities*, 23(4) pp 337-343
- King, N., Horrocks, C. (2010) *Interviews in qualitative research*. Los Angeles: Sage
- La Salle, J., Mitchell, M. (2013) 'Genetics and Environmental Factors in Autism'. *Environmental Epigenetics in Health and Disease*, 2(3) pp. 97-114
- Lee, G. (2009) Parents of Children with High Functioning Autism: How Well Do They Cope and Adjust? *Journal of Developmental and Physical Disabilities*, 21(2) pp. 93-114
- Lin, C. (2008) Coping mechanisms of parents of children recently diagnosed with autism in Taiwan: a qualitative study. *Journal of Clinical Nursing*. 17(20) pp. 2733-2740
- Lincoln, Y.S., & Guba, E.G. (1995). *Naturalistic Inquiry*. Beverly Hills, CA: Sage
- Lindlof, T. (2011) *Qualitative communication research methods*. London: Sage
- Lord, C., Edwin, C. (2013) 'Autism spectrum disorders'. *The science of Mental Health*, 28 pp 217-210
- Luther, E., Daryl, C., Virginia, C. (2005) 'Coping and social support for parents of children with autism'. *The Journal of School Nursing*, 21(1) pp 40-47
- Ogden, J. (2012) *health Psychology*. Maidenhead: Open University Press
- Olsson, M., Hwang, C. (2004) 'depression in mothers and fathers of children with intellectual disability'. *Journal of Intellectual Disability*, 45(6) pp 535-543
- Opdenakker, R. (2006) Advantages and Disadvantages of Four Interview Techniques in Qualitative Research. *Journal of Qualitative Research*, 7(4) pp. 5-11
- Osborne, L. (2008) Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism*, 12(3) pp 309-324
- Ozonoff, S. (2010) 'A prospective study of the emergence of early behavioural signs of autism'. *Journal of the American Academy of Child & Adolescent Psychiatry*, 49(3) pp 256-266
- Mac Donald, J. (2003) *Communicating partners: building responsive relationships in autism*. London: Jessica Kingsley
- Marks, L. (2000) *Qualitative research in context*. Henley-on-Thames: Admap Publications
- Mansell, W., Morris, K. (2004) A survey of parents' reactions to the diagnosis of an autistic spectrum disorder. *Journal of Developmental Psychology*, 8(4) pp. 387-407



- Matson, J., Wilkins, J. (2008) 'The relationship of challenging behaviours to severity and symptoms of autism spectrum disorders'. *Journal of Mental Health Research in Intellectual Disabilities*, 2(1) pp 29-44
- Meirsschaut, M., Roeyers, H., Warreyn, P. (2010) Parenting in families with a child with autism spectrum disorder and a typically developing child: Mothers' experiences and cognitions'. *Research in Autism Spectrum Disorders* 4(4) pp 661-669
- Mesibov, G. (1997) *Autism understanding the disorder*. New York: Plenum Press
- Muhle, R. (2004) 'The Genetics of Autism'. *Journal of Paediatrics*, 5(113) pp. 472-486
- Newman, F., Holzman, L., (1993) *lev Vygotsky: Revolutionary Scientist*. Routledge: London
- Patel, D. (2012) Epidemiology of Autism Spectrum Disorders. *Journal of Clinical Nursing*, 59 (1) pp. 27-43
- Pisula, E. (2010) 'Sense of coherence and coping with stress among mothers and fathers of children with autism'. *Journal of autism and developmental disorders*, 40(12) pp 1485-1494
- Prizant, B. (2000) *Autism spectrum disorders: a transactional developmental perspective*. London: P.H. Brookes Pub
- Potter, D. (2002) The epidemiology of autistic spectrum disorders: is the prevalence rising? *Developmental disabilities*, 8(3) pp. 151-161
- Read, J. (2000) *Disability, the Family and Society: Listening to mothers*. Buckingham: Open University Press
- Richardson, J. (1997) *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*. British Psychological Society: Leicester
- Schall, C., McDonough, J. (2010) Autism spectrum disorders in adolescence and early adulthood: Characteristics and issues. *Journal of Vocational Rehabilitation*, 32(2) pp 81-88
- Sigan, L., Barker, E. (2010) The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Psychological Association*, 24(4) pp. 449-457
- Silverman, D. (2006) *Interpreting qualitative data: methods for analysing talk, text and interaction*. London: Sage
- Skafidas, E., Testa, R. (2012) 'Predicting the diagnosis of autism spectrum disorder using gene pathway analysis'. *Journal of Psychiatry*, 12(10) pp. 12-28

Smith, A., Mulick, J. (2004) 'Sleep problems as possible predictors of intensified symptoms of autism'. *Research in developmental disabilities*, 25(1) pp. 57-66

Southgate, V. (2008) 'unbroken mirrors: Challenging a theory of autism'. *Trends in cognitive sciences*, 12(6) pp 225-229

Steinar, K. (1996) *Interviews: an introduction to qualitative research interviewing*. London:Sage

Taylor, B.(2013) *Qualitative research in the health sciences: methodologies, methods, and processes*. Abingdon: Routledge

Terence, L. (2000) *Quantitative Techniques*. 5<sup>th</sup> ed., London: Continuum

The British Psychology Society (2009) Code of Ethics and Conduct 10

Thomas, P. (2002) 'Coping by redefinition: Cognitive appraisals in mothers of children with autism and children without autism'. *Journal of autism and developmental disorders*, 32(1) pp 25-34

Twoy, R. (2007) Coping strategies used by parents of children with autism. *Journal of Nurse Practitioners*, 19(5) pp. 251-260

Wadeley, A. (1991) *Ethics in psychological research and practice*. Leicester: British Psychological Society

Waterhouse, L. (2013) *Rethinking autism: variation and complexity*. Oxford: Academic Press

Weinberg,D. (2002) *Qualitative research methods*. Oxford: Blackwell

White, M. (2011) *Narrative practise: Continuing the Conversations*. New York: W.W. Norton

Woodgate, R., Roberta, L., Ateah, C. (2008) 'Living in a world of our own: The experience of parents who have a child with autism'. *Qualitative health research*, 18(8) pp 1075-1083