

# **Parenting; mothers' experiences in raising children with autism**

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Research proposal

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## **Abstract**

Autism spectrum disorders are neurodevelopmental disorders that affect a child across his/her entire lifespan. The essential features displayed in children with ASD's are impairments in social communication and interaction as well as restricted repetitive patterns of behaviour, interests or activities. Autism has far reaching consequences which impacts on the welfare, economic state and quality of life, not only for the individual diagnosed but also their families. This is most evidently seen in the primary caregiver, which is predominantly the mother, who not only bears the practical aspects of taking care of the child but is also saddled with challenges, which impacts on their parenting. This research was conducted from an interpretivist paradigm, aiming to explore and describe parenting and mothers' experience. Semi-structured interviews were conducted with ten mothers of children with autism with regards to their parenting experiences of raising a child with autism and the challenges which arise that may impact on their parenting abilities. Conducting a thematic analysis of the data revealed five recurring themes in the data. These themes include, mothers being required to make lifestyle changes in order to accommodate for their child's condition. This meant that mothers were apprehensive about taking their children to public places as to protect them from any harm, thus redefining the ways in which they parent. Furthermore communication and discipline were barriers to effective parenting. However mothers found ways to overcome these barriers. Mothers' reliance on their support systems played a significant role in alleviating the challenges and subsequently improved the ways in which they parent. The lack of adequate resources significantly contributed to the challenging circumstances of these mothers. Participants reported having limited access to appropriate schooling for their children as well as the added financial burden of the comprehensive treatment they need.

*Key words: autism, mothers, parenting*

## **Introduction**

Autism spectrum disorders (ASD's) are neurodevelopmental disorders affecting the child. The essential features displayed in children with ASD's "are persistent impairment in reciprocal social communication and social interaction and restricted repetitive patterns of behaviour, interests or activities" (APA, 2013, p. 53). These symptoms are predominant during early childhood and hinder the way in which these children function in everyday life. Furthermore, the degree of functional impairment in children varies as the features of autism are child and environment specific (APA, 2013).

According to statistics released in April 2012 by the Centre for Disease Control and Prevention in the United States of America, one in every 88 children born will develop an Autistic Spectrum Disorder (Autism South Africa, 2012). With this in mind, since the estimated population of South Africa is approximately 50 590 000, with 19.48 babies being born to every group of 1000, it would suggest that in the year 2012 an average of 985 493 children were born in South Africa, of which 11 198 children were likely to develop an ASD (Autism South Africa, 2012). Furthermore, this then means there will be roughly 933 new cases of children being diagnosed with autism per month, 216 per week and 31 per day hence, every 45 minutes there is a child being born in South Africa who will develop autism (Autism South Africa, 2012).

Since there is an ever growing number of ASD's affecting families and as there is a lack of knowledge surrounding mothers' parenting experiences in South Africa this study aims to explore how South African mothers experience parenting a child with autism and the difficulties they encounter when raising these children. Additionally, this study will attempt to increase the existing body of knowledge.

## **Literature review**

Most parents experience the birth of their child as a blessing and a time of immense joy and happiness. However, once their child displays impairments in social communication and interactions, the way in which they parent becomes extremely challenging and parenting expectations change dramatically (Fisher et al., 2006). These expectations held by parents are usually formulated before the birth of the child and are further modified when interacting with the child (Carter & Kuhn, 2006). Autism could likely be ranked as the most stressful

childhood developmental disorder on the families of these children (Brown et al., 2005). Autism has far reaching consequences which impacts on the welfare, economic state and quality of life, not only for the individual diagnosed but also their families (Beecham, Knapp & Romeo, 2007).

This is most evidently seen in the primary caregiver, which is predominantly the mother, who not only bears the practical aspects of taking care of the child but is also saddled with numerous challenges. These challenges manifest in the form of lifestyle change, termination of employment or limited career progression, loss of income and leisure time, difficulty in terms of communication, as well as available resources (Beecham et al., 2007). This could be associated with the fact that the maladaptive behaviours of autistic children are very pervasive (Carter & Kuhn, 2006).

Due to the fact that children with autism behave in atypical ways, parents' interpretation of these behaviours could have an impact on parental experiences (Carter & Kuhn, 2006). Among studies conducted with 21 families of children with autism (Biedel & Rao, 2009), the majority of mothers reported that the challenges with regard to parenting their children, affected factors such as a lack of spontaneity and flexibility. This meant that they had to plan activities in advance and in turn, this led to decreased participation in family activities (Biedel & Rao, 2009). This contributes to the view that having to parent a child with a neurodevelopmental disorder is a source of great stress and added challenges (Boyd, 2002).

Moreover, mothers reported having to change their lifestyles in order to accommodate their child's specific needs. Thus, the diagnosis of autism is extremely challenging on the mothers as it may hinder their ability to lead a perceived 'normal life' as portrayed in research (Gray, 1997; Bernardes, 1985). Raising a child with autism impacts on their lives in such a way that mothers need to re-examine their priorities in fear of their child having a behavioural response in a public space. It therefore hinders mother's ability to engage in social activities which constitutes part of what mothers of children with autism deem as a 'normal life' (Goin-Kochel, Mackintosh & Myers, 2009; Gray, 1997).

Since parenting a child with autism may prove to be extremely challenging due to the demanding nature of autism, mothers needed to turn into 'superparents', suggesting that mothers became increasingly vigilant and entirely focussed on their child's world for the

purposes of protecting the child (Ateah, Secco & Woodgate, 2008) more so than parents who raise children with other disabilities (Halterman, Magyar & Montes, 2009). This relates to literature which illustrates that mothers who care for children with autism report facing significantly more challenges as compared to mothers who raise children with any other developmental disorders (Brown, et al., 2005).

Research conducted by Gray (1997) depicts the need for mothers to redefine the ways in which they parent their child in terms of communication and discipline. Undoubtedly mothers who are raising children with autism are subjected to challenges as a result of their children's developmental disability and maladaptive behaviours. Moreover mothers are subjected to painful responses from others regarding their child's behaviour as a result of a lack of understanding about autism (Pisula, 2011; Huws & Jones, 2010). Brohart (2008) contended that only parents of an autistic child could really understand just how tricky it could be to discipline their child with autism. It was important for mothers to inform others that they should not be judged for their child's behaviour as they try their best; this was depicted in research conducted by Ateah et al. (2008). Mothers are placed in situations which are unpleasant, bringing about potential for judgement from others as children may display behaviours characteristic of autism (Gray, 2002; Portway & Johnson, 2005). However their appearance is contrary to this, thus leading to judgements of poor upbringing (Farrugia, 2009). This social disapproval of the child's behaviour often leads to mothers experiencing feelings of shame and exclusion from the social activities in which they would normally engage (Farrugia, 2009). According to Knusen and Sloper (as cited in Mohammadi, 2011), mothers were greatly affected by behavioural difficulties the child displayed, in addition to his or her dependency and poor communicative skills.

Children with autism have their own individual ways in which they communicate. However, there are still variations from what mothers raising neurotypical children experience with regards to communication and even more so from what parents of first-borns anticipate (Siegel, 1996). Deficits in communication are evident in children with autism across a range of both verbal and non-verbal skills such as gestures, utterance and facial expressions (Pisula, 2011).

In a longitudinal study conducted by Gray (2002), it was found that mothers regarded communication as becoming less challenging throughout the years. He attributed this change to factors such as an improvement in the child's verbal abilities or mothers broadening their

understanding of the ways in which their child attempted to communicate (Gray, 2002). Additionally mothers reported re-defining their expectations regarding the ways in which their child should communicate as well as accessing more successful ways of mediating the limited communication abilities displayed by the child. Mothers added that they attended various courses to assist with this (Gray, 2002).

Boyd (2002) suggests that one of the chief concerns mothers have regarding parenting is the declined level of support that parents of children with autism receive. Research has shown that support acts as a protective factor for mothers in times of stress or crisis and serves as a mediator for maternal stress (Krauss, 1993; Allen, Han, McCubbin, McCubbin, & Thompson, 1997). Additionally, not having a support system in general has been shown to cause mothers to withdraw from communities due to the perceived maladaptive behaviours of their children, thus further contributing to their challenges (Boyd, 2002).

The first source of support that mothers tend to seek out is their spouses. Subsequently, the larger the support network the better the mother is able to manage the challenges faced (Boyd, 2002). Evidence suggests that important support structures for mothers are firstly their spouses, and this is matched with the mother's relatives, and also parents of other children with autism which could be found at support groups (Boyd, 2002). Mothers seek out these support groups due to the extreme challenges faced when parenting a child with autism (Bitsika, Efremidis & Sharpley, 1997). Likewise, mothers reported that support groups were beneficial as they could engage with other parents experiencing similar situations as well as sharing common concerns and solutions to issues. Furthermore mothers said that it was helpful as it broadened their support structure (Boyd, 2002; Dyson, 1997). Those mothers who received support in the form of their spouses appear to relate better on an emotional level with their children (Boyd, 2002). Increased parental satisfaction in conjunction with some sort of support system leads to increased well-being of the mother, positive attitudes towards the child and increased pleasure during parent-child interactions. (Boyd, 2002).

What should also be noted is that raising a child with autism can significantly impact a woman's life, with mothers potentially feeling that they are missing out on a 'normal' way of life as their children's needs are demanding on them (Ateah, et al., 2008). It is thus not hard to believe that some mothers lose themselves in the process of parenting a child with

autism. Similarly, in all the hype of meeting the needs of these children, it is quite common that the needs of the mothers' are overlooked (Barnard, Prior & Potter, 2000).

According to Ateah, et al (2008), as important as it is for mothers to protect their children, it is equally crucial for them to take care of their own well-being. In addition, evidence suggests that mothers regarded nourishing the self as highly vital in improving their abilities as parents and that when they lose themselves in autism and neglect their welfare, they are not able to adequately care for their children (Ateah, et al., 2008). Irrespective of this, studies using self-reports depict that mothers of children who are on the spectrum have less participation in family or recreational activities than those of neurotypical children do (Boyd, 2002). Therefore, mothers with no form of support and who can't take the time to care for their well-being are at risk of their emotional welfare being compromised (Boyd, 2002).

As is evident from the above literature, mothers face numerous challenges in terms of parenting a child with many developmental demands. In light of this, they require a substantially greater amount of other services, such as physiotherapy, speech and occupational therapy, as well as comprehensive schooling by comparison with children who have other disabilities (Haltermann et al., 2009; Biedel & Rao, 2009). Research conducted in Canada suggests that mothers report concerns surrounding child-related institutions which are established to facilitate the development of the child with autism (Ateah, et al., 2008). Many mothers describe these institutions as being unattainable to them and not adequately equipped. The professionals at these institutions appear, to a large extent, to lack the necessary knowledge and have limited training in this field. All these factors combined with limited resources, suggest these institutions provide little support for mothers and children alike (Ateah et al., 2008). Similarly, studies conducted in the United Kingdom reveal that, although the estimated annual cost set aside for autism in the UK is £ 1 billion (Knapp & Jarbrink, 2000); access to suitable interventions is still low as well as being unevenly distributed, thus perpetuating the challenges experienced by mothers. Barnard et al. (2000) further suggest that parents in the UK require an extended amount of choices in terms of schooling and assistance for autism. Due to the fact that their choices are so limited, many young children with autism are suffering (Barnard et al., 2000).

Contrary to this, other studies conducted by Barnard et al. (2000) in the United Kingdom found that overall, 73% of mothers had reported that they had been satisfied with the education their children were receiving (Barnard et al., 2000). These levels were at their



highest when a degree of autism support was given. This research conducted by Barnard et al.(2000) clearly demonstrates that training staff adequately in autism is vital for meeting the needs of these children (Barnard et al., 2000). There are additional reports depicting that increased numbers of nurseries and primary schools in the United Kingdom are becoming more attuned to the needs of children with autism. Evidence shows that mothers appreciate the provision being made for their children as they feel they are being met half -way by these schools (Barnard et al., 2000).

A nationally representative study in the USA found that more mothers of children with autism between the ages of 3 and 5 years were satisfied with the quality but not the quantity of services their children were receiving as compared to those of children with other disabilities (Halterman et al., 2009). Moreover, parents of children with autism reported significantly poor access to services due to a lack of professionals offering the skills which the child needed, long waiting lists at schools and a lack of sufficient services in the areas in which they resided (Halterman et al., 2009). With further analysis, it was evident that having a child on the spectrum made it significantly harder to access services pertaining to that child (Halterman et al., 2009). Barnard et al. (2000) contended that children may be excluded from schools at one stage or another due to the fact that these schools possess the knowledge of autism but cannot adequately cope with a child's difficult behaviour and will therefore ask parents to take their children out of these schools (Barnard et al., 2000). This speaks to the lack of relevant experience among staff members, as echoed throughout research in the United States (Barnard et al., 2000).

Brown et al. (2005) found that mothers of children with autism seem to report higher parenting stress than mothers who have children with other disabilities. In addition, society's perceived lack of understanding contributes to mothers feeling somewhat isolated and may cause them to feel that their suffering goes unnoticed and that they have to deal with it alone which exacerbates these feelings of stress (Brown et al., 2005). However, according to Tunali and Power (2002) when mothers experience these stressful situations they tend to make sense of the situation by acquiring a different perspective and thus adapt successfully to the situation at hand (Brown et al., 2005; Tunali & Power, 2002).

Evidently awareness and literature around ASD's is still very low in African countries (Ateah et al., 2008; Bakare & Munir, 2011). With this research, the study aims to contribute

to the knowledge gap and in addition, help to highlight the recurrent theme regarding lack of resources and services in South Africa for children with autism.

### **Aim of the research project**

This research project aims to understand the parenting experiences of mothers raising children with autism, who reside in Cape Town. The research question posed was: Is parenting a child with autism met with many challenges, and if so, how do these challenges affect the ways in which these mothers parent their children? Supporting questions were asked in order to probe at other issues, such as:

1. How have mothers lifestyles' changed subsequent to having a child with autism?
2. Are mothers judged by others on the ways in which they parent as a result of behaviours displayed by their children? If so do mothers discipline their children?
3. How does communication with a child with autism redefine the ways in which mothers' parent, if at all?
4. How have support systems affected parenting?
5. What are the effects of either adequate or a lack of resources?

### **Theoretical framework**

As our study focuses on exploring the factors which affect mothers' relationships with their autistic children, an interpretivists paradigm was adopted, as it is seen within qualitative research as one that values the exploration of subjective experiences (Crofts, Hungria, Monfries & Wood, 2011). Interpretivism influenced a huge field of research which illuminated the everyday experiences of people (Crofts et al., 2011), hence the focal point in this approach relates to understanding people's subjective experiences. This has also helped researchers understand social life from the point of view of the individuals that are being studied. The various methods employed within this paradigm are unstructured observations, unstructured interviews as well as personal documents (Crofts, et al., 2011)

Interpretivism has multiple truths and these "truths come into existence in and out of our engagement with the realities in our world" (Crotty, 2005, p. 8). That is to say that meaning within interpretivism is not simply discovered but is constructed and different

individuals may construct meaning in different ways, even when it is connected to the same phenomenon (Crotty, 2005).

We found the interpretivist paradigm to be appropriate for this study as it pivots around the subjectivity of personal experiences and the construction and interpretations of those experiences. It also allows for less of the researchers own beliefs, values and thoughts to filter through (Crotty, 2005).

## **Methodology**

### **Research design**

Qualitative research, an approach used in this study, is said to be a systematic approach that aims to describe life experiences by giving them meaning as they are subjectively presented (Burns & Grove, 2009). The nature of a qualitative study allows a researcher to explore behaviours, perspectives, in-depth feelings and experiences, as we hoped to achieve through this study. Additionally it allows for the quality and complexity of a situation to be investigated through a holistic framework (Holloway & Wheeler, 2002).

Qualitative research proved complimentary to the exploratory nature of the study wherein the factors which affect mothers' parenting experiences of raising children with autism were explored. This was attained through semi-structured interviews in order to gain a richer understanding of these factors. Thus a qualitative interview is considered to be an interaction between the participant and the researcher and this in turn allows for flexibility when planning which questions to use (Babbie & Mouton, 2006). According to Kvale (1996), interviews provide us with a way in which to understand the world from the participants view point. In other words researchers attempt to, in this way, unfold the meaning of people's experiences and attempt to uncover their lived world. Additionally interviews make it possible for a researcher to view the research topic from the perspective of the interviewee (King, 2004). Moreover interviewing is a resourceful way of gaining data for research which requires the analysis of people's opinions (Keates, 2000).

For this study, semi-structured interviews were used to collect data. Semi-structured interviews are advantageous as its flexibility allows for interviewees to be able to freely express their views (Flick, 2002). Therefore, the interview schedule constructed for this study was not followed strictly, but rather was a means to create a relatively relaxed atmosphere in order for participants to express themselves. In this way interviews are

therefore used for obtaining information about people's knowledge, values, preferences and attitudes. During interviews participants led the discussions and as a result, it allowed for information to surface that the researcher had not expected (Field & Morse, 1995).

## **Participants**

Qualitative sampling is concerned with information richness; therefore it is vitally important to identify appropriate participants who can best inform the study (Davidson, Fossey, Harvey & McDermott, 2002). The participants in this study were racially diverse women from the Cape Metropole who had children diagnosed with autism. Of the 10 participants included in the study, 7 were married, 2 were single parents and 1 had a partner, but was unmarried. All the participants possessed at least a basic competency in English.

For this research, mothers who participated in a pilot study around intervention at the Child Guidance Clinic (CGC) at the University of Cape Town were recruited, except for one mother who was recommended by another participant. The sample was conveniently selected and consisted of ten mothers of a child or children between the ages of 3 and 5 years who were diagnosed with autism. While qualitative studies may be done with small samples, the amount of data gathered needs to be sufficient in order to gain in-depth information which will accurately describe the phenomena being studied (Davidson, et al., 2002). Mothers' contact details were obtained from the CGC data base and via a telephonic exchange mothers' were informed about the study and told what the researchers would require from them during their participation. Subsequent to mothers' agreeing to be a part of the study, their appointments were set up to conduct the interviews, at their convenience, either at the CGC or at their homes.

The inclusion criteria for this study required the participant to be the biological mother of a child diagnosed with autism and the children were required to be between the ages of 3 and 5 years. It must be pointed out that the ten mothers who took part in our study are not representative of all mothers within Cape Town due to the small sample size and therefore these findings may not be generalized to all mothers' of autistic children across the broader population of South Africa. In contrast, if the study should be conducted on a larger scale this may be possible.

## **Data collection**

Following a telephonic conversation in which verbal consent was given, interviews were scheduled with the participants. A semi-structured one-on-one interview with the mothers, constructed around the key issues of the study, was used to guide the data collection process (Appendix A). Three of the 10 mothers were interviewed at their homes as they were unable to make it to the CGC, while the remaining 7 mothers were interviewed at the CGC. Mothers were accompanied by their children in order for the researchers to be able to observe the parent-child interactions throughout the interview. Upon starting the interview mothers were given a consent form (Appendix B) which explained the study and requested their written consent to conduct and record the interview via voice recorder. Additionally, mothers were encouraged to ask questions in case they required clarity on the study. All the mothers had, at the least, a basic understanding of the English language and for that reason the interviews were conducted in English.

### **Data analysis**

The interview data was transcribed and any identifying data was removed. These transcriptions were analysed by using thematic analysis which is a type of qualitative analysis that is used to analyse the classifications and themes that relate to the data. It showcases the data in greater detail and deals with various subjects by means of interpretations (Boyatzis, 1998). Also, this analysis is a method whereby themes or patterns are identified and portrays the data set in richer detail (Braun & Clarke, 2006). The data was then examined for relevant themes and links were made across transcripts.

### **Reflexivity**

Reflexivity is intertwined with limitations of a study as it reflects the researchers understanding and thoughts on the impact they had on the research process (England, 1994). In understanding our role as researchers we came to the same conclusions in terms of possible limitations that would be likely to influence mothers' and/or ourselves. Factors we found to be particularly influential was our age compared to majority of the participants as they were much older thus creating some anxiety for us at the start of the interview process. We felt that language was another factor that was influential as some participants did not speak English fluently and this made the participants appear uncomfortable. Even though we were all woman, there was a lack of shared life experiences among us especially when confronted with questions, we did not share the same understandings, and it is acknowledged

that this could possibly be perceived as a barrier. Consistent with literature, a lack of shared experience can potentially hinder the building of rapport and understanding, running the risk of affecting the interview relationship, the quality of the content, and the process of analysing data (Tang, 2002).

### **Ethical considerations**

This study followed the ethical standards specified by the Research Ethics committee of the Department of Psychology at the University of Cape Town.

### **Benefits**

Participants were not offered an incentive to partake in the study as participation was voluntary. However if there was a need for reimbursement, participants were given an unfixed amount to cover the costs of transportation to and from the CGC.

### **Information, consent and voluntary participation**

Participants were requested to sign an informed consent form which stipulated the nature and aims of the study. Additionally, it emphasized that participation was voluntary and that participants' were free to withdraw from the study at any time as well as refuse to answer any intrusive questions. Moreover, informed consent was requested for the interviews to be recorded via voice recorder.

### **Anonymity and confidentiality of data**

Interviews were transcribed and any identifying data was removed from the transcriptions as to ensure anonymity. Additionally participants were given pseudonyms when incorporating their quotes into the study. Voice recordings and transcriptions of the interviews were destroyed after the study was completed.

### **Results and discussion**

For many mothers, parenting a child may provide tremendous happiness but by the same token may be very challenging. Popular media is loaded with conflicting advice on effective ways to parent children (Baron, Groden, Groden & Lipsitt, 2006). Thus mothers are often faced with the worry of perceived hazards their children face every day and concerns around whether they are parenting their children successfully (Baron et al., 2006) due to the fact that autism impairs the children's functioning in their daily lives (APA, 2013). It is then

not surprising that parenting a child with autism may bring about the realization that what these mothers expect their parenting to be, will differ profoundly. In addition mothers of children with neurodevelopmental disorders such as autism, experience greater concerns about parenting their children especially in a country such as South Africa, where resources are limited (Pisula, 2011).

The themes emerging from the data indicated that having a child with autism does affect parenting because autism does not only affect the child but their mothers as well, as indicated by Baron et al. (2006). In this study reported parenting in the context of an ASD diagnosis is defined by the ways in which expectations of day-to-day lives and functioning had to be altered. This largely involved having to adapt multiple aspects of their lives, such as lifestyles and the ways in which they discipline and communicate.

### **Lifestyle change**

The majority of participants in this study reported having to make significant changes to their lifestyles in order to accommodate the demanding nature of parenting a child with autism. Goin-Kochel et al. (2009) indicate that children with autism regularly display behaviours that are disruptive and unmanageable, which may contribute to parents feeling apprehensive about taking the child to public places, for fear of them causing a scene or running into danger. Participants reported not being able to engage in certain activities or to act spontaneously because of the implications for the child, as demonstrated below:

[P8] "... I used to go out all the time but because of his condition he can't just stay with anybody so I will go out for friends' birthdays and my birthday and uhm cousins' birthdays that's the only time we will go out..."

[10] "... cause sometimes I'm scared that he will get lost ...when, in, we are in the shop he will grab everything so I don't want that, maybe the shop owners will not like us so I leave him at home with my mother"

The previous two quotes suggest that lifestyle changes that parents make are motivated by their need to protect their children. They are constantly trying to protect their children from potential physical or emotional harm, negative responses from others as well as from the effects of the changing context, given that children with ASD do not deal well with change or unusual situations, as shown by the following quotes:

[P5] ...it kind of the autism it's because of Lyle he becomes anxious when there's too much people"... "So with certain uhm certain situations uhm whether being uhm a wedding or uhm a birthday party it's a bit too crowded, if I know it's going to be very crowded and the place is not very big and there's not a lot of space for him then I won't go".

[P9] "...I can't take him to a party, he doesn't understand number one, it's a unfamiliar place, its people uhm he don't see every day so he kind of goes into his own little corner and he won't interact... but not the whole part where he would go to the party and there's a lot of people".

What is also clear in the succeeding quote below is the need for parents to consistently be aware of their child's particular difficulties, such as sensory and feeding problems, and to accommodate for this. While this was challenging in some ways, the second quote below further suggests that having to change had some positive aspects for the parents as the changes were actually adaptive for them as individuals:

[P9] "yaw, we used to like just go to the beach like just like that and uhm don't worry about packing in things because you know, can't just do that with him [Jamie] he has a special diet, can't eat certain foods, uhm will he be ok at the beach. He doesn't like sand so he walks with his slippers on the sand on a hot day you know... but he loves the ocean but not all the time, you know I like going to the beach with him..."

[P4] "...*Autism actually forced me to have a plan* cause now your life is calculated and every minute is planned. We have like routine because otherwise not so much with Hakeem but with Shahid a lot of routine and his got transition issues, can't take him anywhere if he doesn't know the place, it's like major meltdown mode..."

Despite the positive aspect in the last quote above, it was evident that the participants were clearly invested to do what was in their child's best interest and made the necessary changes to how they lived their lives. However, this also came at a cost to the participants, such as not having another child because of the risk or to spontaneously leave the house:

[P3] "...we wanted to but we decided after the diagnosis of autism that we wouldn't have another one because of the genetic link and we'd rather give all our time and effort and love and money into one child".



[P7] “It depends because you see Simon, when he becomes like this, I have to watch him, I can’t do anything I can’t work even if I want to go. Somewhere maybe a mall or go to attend a funeral, I can’t just go...”.

Thus, when they needed to go out for social or work purposes, some of the participants reported that it was significantly harder as they had to constantly attend to their child. Others also indicated that they needed to put a considerable amount of thought into planning the trip, even more so than other mothers would usually, as depicted by the statement below.

[P4] “...we hardly eat out unless it’s a place that the kids know. It’s a lot of calculating and planning you have to do which is tiring to the brain. The minute it’s unplanned it can’t happen”.

Overall it seemed clear from the participants’ reports that having a child with autism was a challenge and resulted in significant changes to how they lived their lives. The birth of a child will result in adaptations having to be made by parents (Ateah, et al., 2008). The problems that characterize autism seem to produce particular parenting challenges that result in extreme responses such as avoiding social engagements, because of concerns for the child’s physical and emotional safety (Ateah, et al., 2008). While these changes in lifestyle were perceived as difficult and problematic for the parents, a few participants found some of the changes to be beneficial and positive.

### **Discipline and its effects on parenting**

One of the key reasons reported by most participants for having to make lifestyle changes, particularly in relation to social and recreational activities, was related to concerns that others may not understand their child and thus negatively judge them and their perceived lack of discipline. This is linked to the next major theme that emerged from the data, which relates to the difficulty of disciplining a child with autism and how their parenting was judged negatively by others. Many of the participants indicated that they were subjected to harsh comments made by other people regarding their children’s behaviour. Comments such as “your child is very naughty” were frequently reported by participants, which made them feel as if they were being judged on the way in which their children were parented. However, Brohart (2008) argued that only parents of an autistic child could really understand just how tricky it could be to discipline their child with autism such as depicted in quote below:

[P9] “maybe in a way cause like uhm people like I was saying they judge you and you sit there and think like why, why do you do that you can see that person had a baby and they should know what the challenges’ are especially when you have a special needs child ok but maybe they don’t know”.

[P7] “Ja like before if he doing things like the wrong things I used to beat him. Because I I didn’t know what is wrong with him, but when we go to Red Cross and uhm that that supporting group in Khayelitsha they teach us we mustn’t beat them cause when you beat him it’s worse”.

The last quote above further speaks to the bigger issue related to discipline and how to manage behavioural difficulties in children with atypical development who may not respond to the usual discipline methods in expected ways. In subsequent quotes, the participants indicate that they struggled between being strict and being too lenient, thus not setting appropriate limits as parents:

[P3] “... firstly we let him get away with more sometimes which is our mistake because I can be very strict uhm and sometimes we just go but his autistic, it’s alright, but that’s not acceptable. So we find ourselves doing that, not often but we find ourselves doing that and then we have to put a stop to that.

[P5] “...I get very angry if he if he tries to discipline Lyle I won’t touch Lyle because he doesn’t really understand what’s he’s doing and I tell myself that he needs the attention, let him be, leave him be, his going to learn by playing, just leave him so I tend to I tend to baby him a lot more than I do the others”.

[P1] “uhm yes there is no discipline I’m only starting now to you know, i will hit on his hands er and and but he doesn’t like it, you know he cries so it’s hard to to, because he doesn’t understand that he did something wrong so I would be stern with him and then he would cry and then I have to comfort him so it’s confusing for this child, as, as it is confusing, I know I’m confusing this child, I don’t know what to do”.

Also, in the above quotes, particularly the latter two, participants clearly state that the disorder affects how they perform one of the key parental duties, that of setting boundaries of what is acceptable or unacceptable behaviour. Thus, many participants spoke about the

challenges they faced in terms of discipline, such as not knowing how to appropriately discipline a special needs child or if discipline was even an option.

As we see throughout the participants comments, they are more lenient in terms of disciplining their autistic children because they feel guilty if they are stern as the child, according to them, does not understand what he/she did. Brohart (2008) adds that “too many times, I believed we made the mistake of disciplining our children as one would discipline a ‘normal child’ which is congruent with participants’ reports of not being certain about how to discipline a child with autism. Dissimilar to what Brohart (2008) reports, the participant below reported that she disciplines her child like a normal child and does not feel that this is a mistake in any way as it brings her much wanted results with regard to parenting adequately.

[P2] “...When he’s wrong, why do you do that, don’t do that again, if you do that I’m going to beat you and you sit there. She going to sit. Why you play with your food, if you do that you going in the room. She’s not going to do that again”.

Some participants reported seeking guidance from a support group around discipline and having to try out various strategies. The quotes below also highlight participants’ views that patience and persisting with the strategy is a key aspect of discipline:

[P6] “He’s very stubborn and takes a very long time to come around so bad that I have gone into the stage of taking toys away from him until he apologises. But it takes him quite a while. It does help because he loves playing with his toys...”.

[P 8] “When he has a tantrum I just need to keep calm”... “I just say, I’ll just say no and I’ll stick to my no and I’ll give, like the toy or whatever I’ll put it away uhm he will carry on... so with me if he cries I’ll just leave him to cry, I won’t interfere, I’ll just wait till he calms down”.

### **Communication and its effects on parenting**

Many mothers experienced difficulty in terms of communicating with their children, as their children were either nonverbal or could only say a few words. Mothers then had to redefine the ways in which they engaged with the child, such as having to learn the child’s language in order to improve the way they interact with their children. Research shows that raising a child with autism is challenging for mothers because these children do not "give

back" in the same way other children do. Even though they are responsive in their own ways it still varies from what parents with neurotypical children experience and even more from what parents of first-borns imagined (Siegel, 1996). The following quotes illustrate the ways in which children attempt to communicate with their mothers':

[P8] He will take me to the cupboard, open the cupboard, knock on the fridge. When he knocks on the fridge that means open... so ja it's not actually, for me it's not hard to communicate with him, to know what he wants".

[P5] "because Lyles nonverbal and he doesn't really have a set way of communicating because we've been trying the picture system and it seems to be working uhm so, it, there's times where Lyle wants something or needs something and we don't really know what it is, we try to speak Lyle but ... it becomes really frustrating when we don't know what he wants ...so you kind of uhm you play the game of elimination... you still can't figure out what is wrong with Lyle then it becomes very frustrating coz now what now?"

[P2] "... Why you crying Jill? She's just crying... I don't know why she crying, I don't know what she want, I really don't know... sometimes I can see oh, she was wanting to eat, that's what she was telling me".

It is evident by participants' statements that some mothers communicate better than others and there was a general consensus about having to learn the child's language and adapt and redefine the way in which they parent. For some participants this involved acquiring new skills, and they reported that they attended courses to better understand their children as evident below:

[P4] "I did this workshop... they call it a course... and uhm I did an ABC course that they offering at uhm [name of school] school for autistic learners. The course was, like, a day in the life of a autistic child" ... it makes you reflect on what can I as a parent do"

Despite efforts to facilitate communication with the child, some participants seemed to be uncertain if this would be adequate to understand all the child's attempts at communication, thus raising anxiety about being able to accommodate the needs of their child.

## Support system

Participants in the study had various types of support in order to equip them with the demands of raising a child with autism. Protective factors which can help sustain the mother are effective communication with her family, problem solving and extended family support. This is especially useful in times of stress or crisis (Allen et al., 1997). As a mother, having to fulfil multiple roles is difficult. Having the support of grandparents and the extended family, who are willing to assist with taking care of the child, is an important source of social support. Thus the help of their familial support system was expressed by participants as vital:

[P4] "...and my mother sometimes offers to take care of the kids then we would go out to watch a movie or go out for supper".

[P7] "Simon's aunt, like if I have to go somewhere I take him to her"

[P9] "With my husband... he was more of supporting me cause he could see I was just, I was you know devastated".

[P3] "... I'm very lucky i've got a very supportive husband so I go and I make silver jewellery once a week and ... so i'm very lucky that way and my husband and I have a very good relationship that one of us feels like we need a break we'll just tell the other one and we say just give me an hour and go off and do something or just go and lie on the bed in peace and quiet...".

Throughout the quotes above, participants reported that having some sort of support system was so essential because if, for example, they felt they are unable to do something, got sick, needed understanding or even needed time to themselves, their support system played a big role in assisting them to parent adequately. What is also evident in the last two quotes above is that most importantly, the fathers played a role in assisting mother's to parent effectively, as the father offered a base of support when the mother needed it in terms of having a shoulder to cry on or to give mothers a break when they became overwhelmed.

Another form of support which proved helpful for mothers, was attending support groups. According to Dyson (1997), community-based support groups were fundamental in assisting parents of autistic children. He goes on to say that support groups are beneficial in the sense that they offer mothers a platform to discuss their difficulties, share the coping strategies they utilize and various accomplishments as is described below:

[P7] “it has helped because the parents there they talk about their child I gain things when I’m there because that there’s a lady for example, there’s a lady who tell us a story. She said his child like Simon, she use to do things like Siyanda. Then she said there their neighbours, they, they understand him now cause he try to explain them. She said tell them Simon is a brain problem, that’s why they understand”

Parents that went to support groups found that this was tremendously useful in making things easier as well as understanding what their child was going through. This in turn helped them better understand their parenting role in raising the child. Additionally, although mothers have some sort of support system, overlooking their own needs was seen as a huge problem, as their lives were consumed by taking care of their children. It was difficult for many mothers to take time out for themselves as having a child with autism requires constant supervision. Like many, participant 5 below expresses this clearly:

[P5] “the only me time I have to myself where I actually tell my husband you know what the kids are not coming in the bathroom with me this is my time you keep them... “even if they misbehave I, just give me half an hour ya its, ya time for myself is not a luxury that I have”

Even though some mothers have support there are times when they still feel they have no free time to do anything for themselves. This is evident in the participant’s statement above as she uses bath time as a means to escape from her children’s misbehaving and she views this as time to herself. Another participant reported having time to herself when her child was at school in order to just read a book or do something she enjoys.

In addition, some participants relied on their neurotypical children as a pillar of support. Siblings to developmentally disabled children often become ‘parentified’. That is to say they act more as a parent than a sibling. The risk in being ‘parentified’ affects children regardless of their age. Older sisters often become the second or third parent (Siegel, 1996). For some participants relying on their other children enhanced their ability to parent adequately:

[P1] “Arlene, Arlene helps a lot Arlene is the one that cleans Jacob’s mess you know” ... “I don’t know what I would do without Arlene”... “I wouldn’t know what I would have done if I didn’t have Zarah. Zarah is the one that would say come close the door, mommy’s sleeping you know uhm I don’t know what I and these are children”

Evident in the above quote the participant reported relying on her eldest daughter as well as her 12-year old daughter. She went on to say her 12-year old daughter's marks dropped due to the fact that there was no one to look after her autistic child and therefore her daughter had to watch him straight after school as the participant was at work. In addition support systems, irrespective of the type, proved to be fundamental for many participants as they all reported that they have no idea how single mothers parent their children by themselves without any support, as portrayed by the quote below:

[P9] "I don't know they do it, I don't know. I mean like I meet people like that, I tell them I don't know how they do it because I can see that they are tired and you know they don't have time to and they don't have the support of family members' maybe".

It was evident that participants' different support systems provided a great deal of assistance in order for them to parent effectively as well as some time to care for their personal well-being although it is not sufficient.

### **Lack of resources**

Another theme that was present in our data was the concern about lack of resources in terms of schooling and therapies associated with children on the autism spectrum such as physio -, occupational, and speech therapy. Despite the fact that South Africa has come a long way since apartheid, the problem of the unequal and limited resources still persist, affecting many people especially those seeking resources for their autistic children. Research carried out by Professor Lorna Jacklin in conjunction with Autism South Africa in 2010 illustrated that in South Africa no more than 1% of children with autism are acquiring education of some form. It is believed that this year twice as many children on the spectrum are receiving an education; however the need for further escalation in school placement still exists in order to meet the alarming increase in the incidence of Autism Spectrum Disorders (Autism South Africa, 2012). The following quotes undoubtedly depict participants concern around schooling issues:

[P1]: "there's only two schools that I know of in the Helderberg it's, one is ASAP which is a programme for autistic children and there's the dream tree uhm that one i could never find but ASAP was full, completely. There is, there's not enough uhm help for children in Helderberg especially in here it's like how people do it"

[P7] “We staying in Delft now there uhm I’m struggling cause they doesn’t understand him”.

[P9] “He went for his assessments for two weeks and of those two weeks...when they called us back uhm tell us now what the outcome was, they said his severely autistic so they can’t have him uhm and we were very upset because we know that’s a place for him.”

As seen in the quotes above, many participants were concerned about the problem of finding schools and adequate resources for their children. Additionally, for some participants the resources that are available were not easily accessible or not equipped to care for an autistic child as depicted by the last quote above. However, one participant below reported her satisfaction with the crèche her son was at and felt they were indeed adequately equipped to care for him.

[P8] “...his crèche actually, uhm the teachers there, they also studied autism and things so that’s why it was a good environment to put him in”.

Another problem mothers faced in terms of resources as stated in the quotes directly below was the expense of the school irrespective of the school being accessible.

[P9] “Some schools charge you like R8000 a month and I mean two people can’t afford that much”.

[P3] “but the reality is that I have to work to pay for the therapy and so uhm I mean I always say to my husband if we had a million rand I wouldn’t work then I’d just focus on Mark but the reality is we need to work these things cost money uherrr I feel it’s a bit of a tug of war sometimes I want to I need to work and I want to stay at home”.

The two quotes above represented the sentiments of many participants who shared the problem of the financial strain it could have on them. Similarly to participant 3, other participants said they needed to work as caring for their children was demanding even though they wished they could stay home. Other participants also expressed financial concerns and some participants were even staying home in order to care for their child. It would then not be possible for majority of the participants to afford these fees under these circumstances.



Although parenting was found to be the main theme in the data there was a recurring theme of stress that mothers had to endure because of the demand of parenting a child with autism. The biggest challenge one faces in life is the inability to cope with stressful situations beyond one's control. These situations often require one to make use of strategies where the self is changed to fit the situation. Mothers often employ cognitive and behavioural strategies in order to make sense of their situation by acquiring a different perspective, taking meaning from an event, accepting and positively reinterpreting their position (Tunali & Power, 2002). Hastings (2005) found that mothers of children with autism seem to report higher parenting stress than mothers who have children with other disabilities. Irrespective of greater stress it is clear, that these mothers' adapt successfully when it comes to raising a child who has autism (Hastings, 2005). Participants stated that:

[P3] "we felt terrible for about a week and then we said right and now how do we help him, we came up with an action plan"

[P4] "I think I stop being sad the day I realized it wasn't a death sentence... why you like grieving?"

[P9] "ag but you uhm I , I've overcome that I think that I have accepted the fact that he autistic

As seen in the quotes above, although participants felt that there was much frustration in terms of parenting their children, they all stated that after they allowed themselves time to understand what the situation was, they adapted to it. Therefore they all discussed some sort of positive aspect in terms of accepting that their lives have to change and likewise, they have to learn to parent according to the needs of the child. The above reports from participants speak about how they came to terms with their children's condition, reporting that they have overcome the fact that their child has autism.

## **Conclusion**

The main aim of this research was to explore mothers' subjective experiences in raising children with autism. We found recurring themes which were consistent with literature affecting the ways in which participants parent as there was an alteration in what they perceived parenting to be. With the diagnosis of their children, participants' lives began

to change in tremendous ways as they began to encounter many challenges. Evident from the data was that participants' expressed adjustments and challenges in lifestyles', discipline, and communication. Additionally participants relied on support systems to mediate the ways in which they parent. Themes also included the lack and expense of resources available and the stress that accompanies the diagnosis.

The demand of raising a child with autism changed participants' lifestyles which thus affected the ways in which they parented; this was echoed throughout the relevant literature by Goin-Kochel et al. (2009). These changes came at a cost to participants as they either had to cancel outings or put a tremendous amount of planning into the trips. Likewise participants had to constantly be aware of their children's needs together with protecting their physical and emotional well-being and thus had to parent accordingly as suggested by Goin-Kochel et al. (2009).

Most participants reported difficulty in terms of disciplining their children. Some participants had set ways of disciplining while other participants were particularly conflicted regarding proper ways of discipline. It should be noted that two mothers admitted to using physical punishment as a means to discipline their children, which does not seem appropriate for a child who cannot comprehend right from wrong. This is similar to Brohart (2008) that suggests that mothers often make the mistake of disciplining their children as 'normal' children. One of these participants reported stopping the physical punishment once she received information from a support group that this was detrimental to her child and another mother stated that she hit her child on the hands but immediately followed this with affection, again illustrating the confusion these participants encounter. In addition participants felt that their parenting abilities were being judged by others based on the behaviours their children were displaying. This was found to be consistent with other mothers in studies conducted by Gray (2002) and Portway and Johnson (2005).

Children with autism are unable to communicate effectively and mothers in particular face the challenge of learning the language of the child, thus redefining their roles of interacting and parenting. A study conducted by Gray (2002) corroborates these findings and further stipulates that mothers also attend courses to mediate the communication barrier. Furthermore, it is not unlikely that mothers raising children with autism alter their expectations and experiences of parenting an autistic child as compared to a neurotypical

child (Siegel, 1996). Many participants stated that they understood their children's attempts at communicating however; this understanding only extended into basic needs.

An essential basis for participants are the support systems they utilize to make it slightly easier for them to cope and to better equip them to parent a child with autism. This is also depicted in studies done by Sharpley et al. (1997) and Boyd (2002), which reaches the same sentiments to that of the participants' in this study. Support structures varied from grandparents of the child, to fathers and the participants' other neurotypical children. This was largely the types of support mothers' in other studies seek (e.g. Boyd, 2002). Despite the use of support systems, most participants still felt that they had little time to themselves because the greater part of parenting was still their responsibility. Few participants stated that they had the time to take care of their own well-being or engage in an activity for their own personal enjoyment. This was consistent with mothers' in another studies by Ateah, et al. (2008) contending that caring for a child with autism could very easily dominate their own personal needs.

Another major difficulty was the lack of resources for autism in South Africa and the consequences thereof. Participants reported the extreme financial burden of the various treatments their children needed and in addition found extreme difficulty in locating a school, affording the school and if schools were located some were not equipped to care for the child or it had reached its intake capacity. This was on par with literature piloted in US, UK and Canada (Ateah, et al., 2008; Bernard et al., 2000; Halterman et al., 2009). Contrary to this was another study led by Bernard et al. (2000) which concluded that mothers' were content with the education their children were receiving. Thus it was consistent with the minority of the participants' in this study who were satisfied with the crèche their children attended.

Lastly although the redefinition of parenting seems to be the biggest theme in the data, the evidence of stress experienced by the participants' was apparent. Irrespective of the stressful nature of caring for these children, each and every participant became positive about their situations, stating that they dealt with obstacles when it came their way. This relates strongly to literature by Hastings (2005) and Tunali and Power (2002) who conclude that mothers' usually attain an altered perspective and adapt accordingly. Since many participants did not have a parenting plan, they expressed that having a child with autism forced them to make plans and this was regarded as positively impacting their lives.

Throughout the study it became evident that there is a somewhat universal lack in adequate resources for autism however; the body of knowledge surrounding autism seems to vary extensively. The body of knowledge available which documents this lack of resources in the US, UK and Canada, is depicted largely through literature than compared to South African literature, which is extremely limited. As a result this gives a less comprehensive understanding of the scope of autism in South Africa. Future research will have to focus on building on this body of knowledge thus helping to initiate the implementation of appropriate resources for children with autism and their mothers.

The need for adequate and accessible resources and knowledge around autism is vital in South Africa. While conducting the study it was problematic to obtain research on autism in South Africa despite consulting numerous sources. What was gathered however was that participants consulted the internet, which to their dismay depicted the worst case scenarios or gave misleading information. Although there are resources available in South Africa these are few and each has their own challenges. Although the scope of autism in South Africa is very limited, it was clear that we have just scraped the surface of the challenges mothers face in parenting their children with autism, especially in a country which is still affected by its past. Thus the accessibility to resources is vital because despite the fact that mothers have support structures, it is still not adequate to successfully meet their needs. Mothers need additional support, knowledge, and resources to strengthen their parenting abilities and therefore the urgency for education and resources around autism needs to be stressed.

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**APPENDIX A: INTERVIEW SCHEDULE****Title: Exploration of mothers' interactions with their autistic children**

1. When did you first realize that your child has autism?
  - What signs did you notice?
  - What steps did you take once you picked up that there could be a potential problem?
2. How did you feel when your child was diagnosed with autism?
  - What were your thoughts?
  - How did the diagnosis change the way in which you parent your child compared to when you were unaware that s/he has autism?
3. How would you describe the relationship you have with your child?
4. Do you find it difficult to interact with your child?
  - How does this make you feel?
  - How does your child respond when you are being affectionate?
5. What do you find most challenging about raising a child with autism?
6. Is there anything else that you would like to share about your relationship with your child?

**APPENDIX B: CONSENT FORM****CONSENT TO PARTICIPATE IN A RESEARCH STUDY**

**Dear parent**

**Invitation and Purpose**

This study will be conducted by Terri-Lee Barends and Rushdah Mohamed. For the purposes of this study we are interested in exploring mothers' perceptions of the interactions and attachment they share with their children who are autistic. You are being asked to participate in the study because you are a mother of a child who has autism.

**What happens in the study?**

If you agree to join the study you will be asked to have at least one interview with the researcher. Each interview will last about 1 ½ hours. The interviews will take place at the Child Guidance Clinic at the University of Cape Town, during the week but at a time that is most suitable to you.

**Voluntary Participation**

Your participation in this study is completely voluntary. Your decision to not join the study will not affect you in any way. If you decide to join the study you can leave it at any time. You do not have to answer any questions that you feel are too personal and make you feel uncomfortable.

**Privacy and Confidentiality**

The interviews will be recorded to ensure that we recall everything that we have spoken about; however strict precautions will be taken to keep information about you confidential throughout the study. Your name will not be used in anything written about the study. The recording will be stored in a locked cabinet at all times and only the researchers will have access to it. It will be destroyed when the project comes to an end.

