

An Exploration of the Lived Experiences of Mothers Raising Children with Autism

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ABSTRACT

Autism is a severe childhood developmental disorder that poses unique challenges and implications to families. Mothers have to re-define their journey of parenthood once their child is diagnosed with autism. Using a phenomenological approach, this study sought to explore and describe mothers' experiences of having a child with autism. Semi-structured interviews were conducted with ten mothers of children with autism regarding their experiences of the pre-diagnosis phase, diagnostic process and post-diagnostic adjustment. A thematic analysis was used to extract common themes from the data collected. The findings indicate the presence of multiple challenges for mothers as they attempt to make sense of their child's non-typical development in the context of the child's apparent typical appearance. Upon receiving a diagnosis of autism, participants reported that they experienced a complex set of responses which included initial and on-going confusion regarding what was being communicated by the attending professionals. Mothers reported that they went through a grief-like process that involved mourning the loss of the child they expected and a parenting journey they had envisaged. Participants also described having to make lifestyle transitions, such as in their careers, family activities and relationships with their non-affected children. A key challenge reported was the sense of disempowerment and helplessness as they struggled to secure placement at schools for children with autism. The findings suggest that professionals need to engage more with families when conveying a diagnosis of autism, particularly with families from low socio-economic backgrounds. Thus, the findings suggest that there is a need to be attentive to the challenges facing poorly-resourced families in order to advocate for the necessary support and facilities.

Key words: Autism; autism spectrum disorder; mother's experiences; family, psychological effects; positive experiences; diagnosis.

Introduction

Autism is a childhood developmental disorder that is characterised by three essential features; a combination of impairments in (1) social interaction and (2) communication, and (3) restricted, repetitive, and stereotyped patterns of behaviour, interests and activities (American Psychiatric Association, [APA], 2000). Although children with autism are challenged with learning difficulties and behaviour problems, movies such as *Rain Man* have contributed to the stigma and discrimination of these children by portraying them as mentally challenged children gifted in mathematical calculations, music and art. In reality, autism is a serious childhood pathology in terms of its severity and impact on family (Altiere & von Kluge, 2009). Parents of children with an Autism disorder face a unique set of challenges that affect their psychological and emotional well-being.

The number of children diagnosed with an Autism Spectrum Disorder (ASD) is increasing at an alarming rate (Rice, 2009). The current estimated number of children diagnosed with an ASD in the USA varies widely, with one study estimating that 1 in 91 children were diagnosed in 2007 (Kogan et al., 2009), while the Centers for Disease Control (CDC) estimated that 1 in 150 children were diagnosed in the same year (Rice, 2009). While estimates may differ, it is clear that there is a large percentage of American children diagnosed with autism.

To my knowledge, there are no reliable local South African statistics available but it is unlikely that the numbers would be any lower with a disorder that knows no status, colour, or nationality. The number of children diagnosed with autism suggests that there is a high number of families faced with unique challenges in caring for the child. This study aims to explore how primary caregivers are challenged by raising a child with autism. As mothers traditionally have served as the main caregivers for children and the family (Lutz, Patterson & Klein, 2012), the researcher argues that mothers experience more challenges in their journey of parenthood in caring for such a child.

Definition of terms

Parents. For the purposes of this study, the term “*parents*” will be used to refer to the mothers of children with autism who serve as their primary carer and are responsible for the maintenance of these children.

Autism Spectrum Disorder. The term is a broad category containing similar developmental disorders into which Autism Disorder falls.

Parental Experiences

Parenting is in itself a challenging experience and could be even more difficult when raising a child with autism. Previous research on families caring for children with autism has traditionally focused on the impact parents have on the child, not the child's effect on the parents. More recently, studies have focused on the challenges that parents face in raising a child with autism and the different adjustments in family life they have to make to accommodate the special needs of these children (Gray, 2002). Thus, parents of children with autism face unique demands in raising and supporting their children. Therefore an understanding of the experiences of parents of children with autism is crucial in providing the necessary support and facilities.

Parents' Experiences of the Period before Diagnosis

The phase before diagnosis could be particularly stressful for parents as manifestations of the disorder are often vague and ambiguous. Autism is unique to every child and can be difficult to recognise in children between the ages of 2 to 5 as some of the signs that lead to a diagnosis, such as the child's socialisation skills and communication with peers, do not become apparent until the child is older (Crown, 2009). However, parents' early concerns include speech, language, pointing and awareness, rituals, eye contact and behaviour problems which they often become aware of months before professionals diagnose their child (Ahern, 2000). During this period, parents experience feelings of anxiety, stress and confusion as their child's problems become prominent and while they find it difficult to understand the child's development (Gray, 2002).

According to Moh and Magiati (2012), educated parents with more economic resources may be more alert in noticing their children's atypical developmental earlier, despite the severity of the symptoms, and may thus seek help earlier. It is suggested that parents from low socio economic and deprived educational backgrounds may either not notice or understand non-typical behaviour or development earlier (Davis & Carter, 2008). Lack of knowledge makes it difficult for the parent to seek professional assistance and may result in some parents resorting to using the media and other people's experiences to provide a home diagnosis of the child (Glazzard & Overall, 2012). Additionally, mothers from well-educated backgrounds may be in fear of the possible diagnosis of their child because they are aware of the implications of the disorder, whereas mothers who are less knowledgeable on the disorder may experience higher levels of confusion and may have hope that once the child

is diagnosed, she/he will be treated (Gray, 2006). Mothers who understand the disorder will therefore have their worst fears confirmed when their child is diagnosed.

Parents' Experiences of the Diagnostic Phase

Moh and Magiati (2012) have reported that parents experienced more stress during the diagnostic phase if they had numerous doctors to consult at this stage, as they would be required to consult with professionals such as psychologists, psychiatrists, speech therapists, occupational therapists, and physiotherapists. This may in part be attributable to the fact that they typically are overloaded with new information which could be difficult to assimilate, making it complicated to think about the implications for the future of their children. This period is also a pivotal phase in terms of intervention, as earlier intervention may help to mediate the outcomes for both parent and child over a longer developmental period.

Ahern (2000) suggests that helping professionals are the most important mediators because they have the potential to become an initial social support structure for care givers. However, the author reported that helping professionals responded negatively to parents' early concerns regarding delayed development of their child, a finding that has been reported in other studies (e.g Boushey, 2001; Roth, 2001). Helping professionals often dismiss parents' early concerns and assign other reasons to the child's development, which contributes to feelings of disempowerment and confusion (Shall, 2000). It thus seems that helping professionals can have a profound impact on mothers' responses to initial concerns, as well as to responses around the diagnosis.

According to Boushey (2001), parents of children with autism move through a process similar to a grief cycle after receiving a diagnosis of their child, as they experience feelings of initial shock and denial, loss, anger and final acceptance. Osborne and Reed (2008) state that initially parents experience a sense of relief that their suspicions have been confirmed and that there is a name for their child's condition. This degree of explanation offered by the diagnosis also helps parents accept that they are not to blame for their child's disorder (Mansell & Morris, 2004). *Grief* is used analogously, as the process involves the loss of a life they had hoped and expected to have and the prolonged emotional experiences and psychological re-adjustments that mothers have to undergo throughout the different stages of the child's developmental milestones.

Parents' Experiences of the Post-Diagnosis Phase

Research suggests that the challenges of caring for a child with autism can result in pronounced psychological distress for parents (Davis & Carter, 2008; Ekas & Whitman, 2010; Hastings, 2008), reflected not only in the impact of diagnosis, but as well as in the specific and on-going psychosocial, developmental and behaviour challenges in the process (Eisenhower, Baker & Blacher, 2005). There is the acknowledgment of potential loss of self and family image and livelihood, which implies a unique parenting experience with different expectations, hopes and dreams for the child and family (Woodgate, Ateah & Secco, 2008) to what they had anticipated.

However, a number of factors related to the disorder influences parental responses and stress levels. Ekas and Whitman (2010) indicate that greater severity of ASD symptoms is directly related to increased maternal stress. For example, children with ASD can have interrupted sleep routines, such as waking earlier than a normally developing child, which is likely to contribute to fatigue for mothers (Glazzard & Overall, 2012). This is known as chronic partial sleep deprivation (Meltzer, 2008). Similarly, although feeding challenges are present in typically developing children, they are considerably greater in children with ASD. Children with autism have more mealtime challenges than their siblings (Nadon, Feldman, Dunn & Gisel, 2011; Rogers, Magill-Evans & Rempel, 2012). Mealtime challenges include not staying seated during mealtimes, eating at different times without the family, eating specific types of foods, and having periods of insistent eating the same foods (Nadon et al. 2011). There is a strain on mothers when planning meals in a family setup that has to accommodate the affected child and other family members.

Davis and Carter (2008) indicate that parents differ in their ability to manage and respond to the challenges related to the child's autism. Some parents experience significant mental health problems, while others experience relatively few of these (Benson & Karlof, 2009). Studies suggest that the impact of autism may also differ depending on whether parents focus more on the negative characteristics and deficiencies in the child, such as behaviour problems and symptom severity (Ekas & Whitman, 2010). Parents may focus on the positive attributes and accomplishments of the child, and these experiences appear to relate to lower levels of parenting stress and can be a buffer against psychological symptoms (Kayfitz, Marcia, Gragg & Robert Orr, 2010). For example, these authors state that there are mothers who, while reporting higher levels of care-giving demands from their children with intellectual disabilities, also reported more personal growth and maturity. Thus while reports

are mostly of negative outcomes for parents, some studies report positive ones as well (e.g. Woodgate et al., 2008; Eisenhower et al., 2005).

Challenges to the family system. In addition to the intrapersonal impact of having a child with ASD, parents' relationships with others may be affected. A child with ASD can have a particularly negative impact on the marital relationship (Lee, 2009), as well as on a parents' social life (Altiere&von Kluge, 2009). The mother, often the primary carer, has to restrict time that was previously used for her spouse and friends because of the additional time demands for caring for the child. Parental stress and the demands placed on them also have the potential to negatively impact on the family system, including siblings. Meyer, Ingersoll and Hambrick (2011), for example, point out that siblings of children with ASD displayed higher rates of adjustment problems than those without. However, this relationship was found to be mediated by maternal depressive symptoms; a parent who is experiencing high levels of depression may find it difficult in balancing the needs of several children with different developmental demands and may be unable to provide the required emotional support and discipline for all the children (Nadon et al. 2011).

Notably, most studies reviewed (e.g. Altieri&von Kluge, 2009; Lee, 2009; Nadon et al., 2011; Meyer et al., 2011) do not acknowledge the influence of socio-economic status when discussing the impact of autism on parents and that finances can be a buffer against the challenges of autism. Parents who are wealthy may react differently to those who have financial difficulties, possibly due to the support for their child that they are able to access. Baker and Drapela (2010) have pointed out that children with disabilities may benefit from having a mother who does not take up employment outside the home. However, this poses serious financial implications for the family, taking into consideration the costs involved in managing the disorder and associated problems, such as therapy, doctors' consultation, special dietary requirements, and special education for a child with autism.

Although the literature explores and describes the experiences of mothers raising children with autism, most of the studies reviewed do not differentiate the experiences of mothers and fathers but group them together. For this study, it was deemed imperative that mothers and fathers' experiences are accounted for separately, based on the assumption that, as primary care-givers, mothers are likely to experience substantially higher levels of psychological and emotional distress than fathers. Therefore, studying the phenomenological accounts of mothers' experiences regarding the impact of a child with autism was a logical beginning. It is important that future research take into account that resources determine the nature, quality and quantity of available assistance for children with autism. It is hoped that

perspectives of different mothers regarding the way they engage daily with their child within their context will inform policy and practice around intervening in a resource-strapped context. Also, previously published studies tend to focus on the negative experiences of raising a child with autism with a few that explore the possibilities of positive experiences. Therefore this study aims to further investigate these experiences that have seemingly not been reported in the literature.

Methodology

Aims and Objectives

The overall aim of this research was to understand and provide a description of the experiences of Cape Town mothers raising children with autism. The research aims to provide insight into how mothers with children with autism experience the pre-diagnostic phase, how they adjust to family life after diagnosis, and other concerns regarding the future of their child.

Main Research question: What are the lived experiences of mothers raising children with autism?

Secondary Questions:

- How do mothers with children with autism experience the period before diagnosis?
- To what extent are health professionals available to help mothers during the diagnosis process?
- What is the impact of a child with autism on other members of the family?
- How do mothers adjust to family life after diagnosis?

Theoretical framework

This study is situated within a phenomenological framework. Phenomenology attempts to generate knowledge about how individuals experience phenomena (Hesse-Biber & Leavy, 2005). The aim of phenomenological research is to understand and describe the participants' experiences of their everyday world as they see it (Padgett, 2008). Thus, this approach was appropriate for a study of this nature, the aim of which was to understand the subjective experiences of women who are raising children with autism. Phenomenology therefore allows the researcher to identify mothers' experiences within the specific context of

their subjective realities, and with this understanding the study aimed to develop interpretations of these experiences.

Research design

Qualitative Methods. Qualitative research involves an interpretative, naturalistic approach to the world (Denzin & Lincoln, 1994). Qualitative research is conducted in order to understand the contexts within which participants engage with an issue (Creswell, 2007, p.40). A qualitative design fits the exploratory nature of this study because it will allow for a detailed exploration of the mothers' experiences, as qualitative research acknowledges that there are multiple truths and that a person's interpretation of their experience is dependent on their social context (Goldman & Du Mont, 2001). Qualitative data collection methods, such as individual interviews, allow for the collection of rich data, as open-ended questions are used to enable participants to describe their experiences in their own words (Babbie & Mouton, 2006).

Participants

Participants were recruited from a cohort of parents whose children were participating in a research project investigating the suitability of an intervention for the South African Early Start Up Denver Model, being conducted at the Child Guidance Clinic (CGC) at the University of Cape Town. Purposive sampling was used to select ten mothers of children diagnosed with autism. The participants came from low socio-economic backgrounds and all had a basic level of competency in English. Eight of the ten mothers were married, three were Xhosa speaking and for seven participants, English was their first language. They were all parents of male children aged 4-5 years.

Data Collection Tool and Procedure

Data was collected through the use of semi-structured face-to-face interviews. A semi-structured interview plan (Appendix A) was used to guide the interview, however the interviewer did not follow a linear process during the sessions but adjusted the interview plan according to each participant's needs to allow for an unlimited opportunity of self-expression (De Vos, Delpont, Fouche & Strydom, 2011). In this way, in line with phenomenological research, an interview places the participant as an active participant and expert in her own life, validating her knowledge and contribution to the research process (Gill & Liamputtong, 2009).

Permission to access the list of names of the cohort of mothers was sought from the CGC. The participants were contacted telephonically by the researcher to obtain consent and set up appointments. The interviews were all conducted in English and took place at the CGC and participants' homes. The familiarity of the places was likely to contribute to relaxed atmospheres, enabling open self expression. The researcher explained the nature of the study to the participants and with informed consent (Appendix B) the interviews proceeded. The interview sessions were between 45-75 minutes. The first questions delved into the mothers' personal journeys of parenting a child with autism, probing into their experiences and concerns, as well as offering an opportunity for them to share how they coped. The questions purposively allowed the participants to reflect on their experience, which was seemingly difficult to express as mothers struggled to articulate their feelings. In some participants, the questions elicited emotional reactions such as teary eyes and crying as mothers shared their stories.

Data Analysis

The data collected was analysed using thematic analysis. It is a flexible way of creating meaning from sets of data and allows for thick descriptions to emerge (Braun & Clarke, 2006). Due to the exploratory nature of the study, this approach was suitable as the aim was to explore and report on participants' experiences on their parenting journey. The researcher followed Braun and Clarke's (2006) step-by-step guideline to discover themes pertinent to the research question.

The recorded interviews were transcribed and all identifying data was removed. Inductive thematic analysis was used; a process that involves observing themes as they emerge from the data without imposing preconceptions, and allowing for the organisation of themes within the data (Boyatzis, 1998). The researcher colour-coded interesting passages which were then grouped together in categories. The relationships between these codes were investigated and the researcher identified thematic connections within and among them, in order to produce transcriptions that were thematically organised. Furthermore, in line with phenomenological research, the researcher paid attention to both explicit and semantic meanings that emerged from the data, taking into consideration that language may affect participants understanding of their experience (Gill & Liamputtong, 2009).

The researcher engaged in a recursive process throughout the analysis which required the researcher to move between the data to ensure that relevant themes to the research question were identified. It was expected that certain themes would emerge, as informed by

previous research. However, it was hoped that new themes would appear due to the questions that were asked. To ensure trustworthiness and validity, the researcher maintained reflexivity throughout the process (Braun & Clarke, 2006).

Ethical Considerations

Ethical approval for conducting the study was granted by the Psychology Department Ethics Committee, University of Cape Town.

Informed consent. The research participants were requested to sign an informed consent (Appendix B) form which provided an accurate description of the nature and aims of the study. The form clearly emphasised the voluntary nature of the study and that their participation would not in any way affect the intervention their children received. The consent form additionally highlighted that the researcher was a student and not a staff member in the intervention. Also, their right to withdraw from the study at any time without any consequence was clearly stated. Participants were further requested to sign an informed consent form for the interviews to be audiotaped.

Potential risks and benefits. It is possible that participation in the study may have elicited mild psychological distress related to the disclosure of information of a personal and potentially difficult nature. The participants were offered referral sheets (Appendix C) where they could initiate contact with a therapist if the interview became distressing. Participants were given R20 as reimbursement for transportation costs that they incurred in participating in the study. The participants were not offered any monetary gains for their participation in the study, as this was purely on a voluntary basis.

Privacy, anonymity and confidentiality of data. All audiotapes of the research interviews were transcribed and coded to ensure anonymity and confidentiality of the participants' data. The audiotapes were destroyed upon completion of the research project. Pseudonyms will be provided for any subsequent publication of the research results.

Limitations of the Study

The study was limited by the fact that the interviewer was not conversant in Xhosa, as some of the participants spoke Xhosa as their first language. While some participants were fluent in English, others were not fully competent in the language. It is possible that meanings may have been lost between the researcher and participant during the interview process as a result of the language barrier. Furthermore, the relatively small sample size (10) of the mothers may not be representative of all mothers raising children with autism. The

sample consisted of mothers whose children participated in an intervention programme offered by the Child Guidance Clinic and thus the study does not explore experiences of mothers not affiliated to the clinic. It could therefore be said that mothers in the sample, who have had intervention for their child could have different experiences to mothers whose children have not received any form of assistance. However, the aim of this study is not concerned with generalizing the sample to the broader population, but rather to explore the unique experiences of this group of individuals (Babbie & Mouton, 2006).

Reflexivity

In an attempt for me as a researcher to understand how my role influenced the research process, it is imperative that I assert my position. It is a way of evaluating how the inter-subjective elements I carried may have impinged on and transformed the research (Finlay, 2002). My gender, class, age, and background may have influenced how participants interacted with me and their willingness to share information. This included the power dimensions in the research relationship, together with broader implications of the study (Parker, 2005). As I provided the mothers with letters informing them of the details of my study, it required that I inform them that I would be representing the University of Cape Town. Thus, this placed me in a different location to theirs, and one of hierarchy, where the mothers had learnt to respect or not. As the University of Cape Town provided intervention for their children, the mothers may have been in considerable admiration of it and have assigned a prestigious status to me.

This position of hierarchy and respect is well demonstrated by *P3* who said “*If here at the child guidance, if you can help me find a school for him it will be better*”. The participant appears to have been hoping that my position could initiate efforts that would assist her although I did not have the power to do so. On the other hand, it may have been negatively received by the mothers because this representation placed me in an irreconcilable position of difference to them due to class differences. I was also acutely aware of how my class and educational privilege (through material and symbolic differences) differentiated me from the mothers since most of the mothers were from under-privileged backgrounds.

Conducting research in South Africa as a non-national brought different dynamics in terms of being regarded as an outsider and also, politics of representation. This positioning of *other* by participants may have been regarded as my inability to understand the South African context in which mothers raising children with autism situate and mothers could therefore have imparted their knowledge with the aim of educating me. Being seen as an outsider by

the mothers may also have initiated the belief that I was taking an impartial stance in the research which may have improved rapport between the mothers and me. Our commonality of gender would have facilitated this rapport which would have allowed for mothers to share their knowledge and experiences. Therefore, I acknowledge the differences between myself and the mothers and understand the influence I may have had on the overall research process (Parker, 2005).

Results and Discussion

This section presents a detailed discussion of the results. The first part looks at the mothers' experiences during the pre-diagnostic phase and is followed by the participants' account of their reactions to the diagnosis phase. The last section relates to the impact of the diagnosis on the mother and the entire family system, as well as their concerns about the future of their child. A transcription key (Appendix D) is provided for ease of understanding of the data presented in the findings.

Recognition of Atypical Development

Mothers in this study reported being aware of early abnormalities in their child's development. Participants repeatedly confirmed the outward normal appearance of their newborn child, and the complete absence of any visible features suggesting the presence of a developmental disorder. This is consistent with Ahern (2000) who notes that parents often become concerned with their children's development months before professionals become aware of the signs and before a diagnosis of autism is made. Participants reported speech, language, pointing and awareness, rituals, eye contact and behaviour problems as early areas of concern.

By the time he was two and he (.) was then at that point totally silent. He wasn't even making (...) he used to say, "daddy", "mummy", "bye". He used to call his grandparents and then he just became a silent child and pretty obsessive with certain things. (P1)

There is still no speech but he cried a lot, he was cranky and he just didn't do things, (...) he was just staring and quiet, and I didn't know if he was hungry or wet. I kind of picked it up from the start. I knew there was something wrong. (P7)

He wasn't talking, he refused to say anything. I'll show him a flash of cards with fish on it and he just wouldn't say it. He started making this hard pitched iiiiii sound (demonstrates) all the time, (.) constantly and he did strange things like (...) he would watch the bicycle wheel go round and round and then try to put his tongue in the spokes. (P2)

The communication and social interactive difficulties reported by participants are in fact a key characteristic of the disorder. Similar to findings in Midence and O'Neill(1999), the mothers in this study reported feeling confused by their children's early behavioural difficulties and developmental delays in the context of their normal appearance. In seeking to make sense of the observed symptoms and problems, the participants indicated that they used sources such as parenting books and some the internet, as well as consulting other women about their experiences.

You read up, umm, in all these parenting books and I used to watch this programme on TV, (.) I can't remember what the name is and she used to say that when your child is tired, or he is sleepy, (.) er, he won't make eye contact (...). (P1)

And I just threw myself into getting every single piece of information I possible could on autism (...). I just sat at the computer every single night after that child went to sleep (.) I was on the computer till four and five in the morning doing research on autism. (P2)

Someone mentioned to me about autism, I didn't know what it was, so I didn't bother with it. Then after a while I read up on autism, and then I realised that there is, (...) it explains some of the symptoms and that is when I decided to have him assessed. (P10)

Thus, the period before diagnosis appears to be particularly difficult for parents while they try to make meaning of their child's behaviour. The participants often felt anxious and fearful at the possibility that something might be wrong with the child, and fatigued by their inability to understand the child's development. The participants reported that not understanding their child's behaviour and not knowing what was wrong with the child was difficult and distressing. They described the period before receiving a diagnosis as the most stressful time in their lives, as also reported by Howlin and Moorf (1997). It was also during this period that the participants in this study indicated that they often felt guilty that they were not doing enough to help their child as their child's abnormal development became harder to manage.

They reported that valuable time was lost in which the child was not receiving any form of intervention while they were still trying to make sense of the signs.

We were losing a lot of time because we were trying to get a diagnosis, we weren't doing any therapies, and we weren't seeing the correct people, so it was like chasing our tails, so it was a bit crazy. (P1)

It took us six months, I think, to get an appointment with her ((paediatrician)), so it was that wait. I didn't know what to do because nobody could tell me: This is the next step. Nobody could really guide us as to what to do and that was frustrating. (P7)

And yes, I regret ignoring the signs before I had him assessed. (P10)

The reported emotional hardship of confusion, anxiety and stress during the pre-diagnostic phase as the children's problems became more prominent are typical parental responses in the presence of atypical behaviour (Gray, 2006). This emotional turmoil contributed to parents contacting health professionals in search of answers. Overwhelmingly, participants reported that health practitioners were not helpful at this stage but rather contributed to their feelings of helplessness and confusion when their concerns were considered to be excessive anxiety on their part. Participants also reported that health practitioners tended to assign other reasons to the behaviours of the child and not provide validating answers for them.

She ((paediatrician)) would always say, "Don't worry, boys take longer to speak, you are putting too much pressure on him." (P1)

I took him to ____ first and they sent him to an occupational therapist because they checked him and they said he is fine. And she ((occupational therapist)) said to me she thought he might have a bit of ADD. (P6)

Because of his global development delay I took him to ____ ((hospital)) for speech and I took him to ____ ((hospital)) for physio and all of that, (.) until I met a lady called ____ and she said to us, "I think your son is actually deaf", and I said, "No, it can't be because he had everything tested. I went for AVRs and everything and twice we did that." (P7)

It is apparent from the extracts above that helping professionals' constant dismissal of parents' concerns left them feeling powerless and hopeless. As Midence and O'Neill (1999)

point out, until diagnosis is complete, there is often little that parents can do to address their child's difficulties.

Reaction to the Diagnosis

For all of the mothers, the diagnosis gave them a sense of empowerment as finally, they had hope, information to learn, experts to find, and an explanation for their child's differentness (Schall, 2000). The availability of a label seemed to initiate efforts towards helping the child, as shown below:

It was it was a relief, on my side it was a relief. It was like, finally this thing has a name. Now I know what is wrong with my son, (.) for me it was just relief. (P1)

So frustrating, but made easier because I know what I am dealing with. I know why he is acting like this to that. I know why he's reacting to that. I know why he doesn't want to eat that. You know, everything sort of falls into place. (P2)

I think the worst part is not actually knowing, but when someone tells you what it is then you can work on the problem. It is difficult working on something when you don't know what the problem is. (P10)

The participants talked about the difficulties involved in explaining their child's situation to other people and referred to the diagnosis as a solution to this, which correlates with the sentiments of parents in other studies (Gray, 2006). It was noted that intense relief was particularly felt by first-time mothers, who reported that because of their lack of experience and knowledge, they had begun to compare their children with others and saw the developmental lags as a reflection of their poor parenting skills:

You know, for me it's if a school rejects my son because he is not potty-trained I feel it's a reflection on me, that I didn't do enough. (P10)

So it was totally chaotic because I was still dealing with being a first-time mum, then the first time, my first son was like, not developing at the normal pace. (P1)

These experiences are consistent with research which showed that, after some time, mothers question their parenting skills when comparing their child with his/her peers (Lasser & Corley, 2008). They regarded their inability as a parent as the cause of their child's abnormal development and felt they were doing something wrong, and ultimately were vulnerable to criticism from external people about their bad parenting skills. Although

the diagnosis offered an initial sense of relief, participants reported that they still had to deal with harsh criticisms from family members, such as grandparents, aunts and uncles, as well as the general public.

Very recently we had an argument; we, umm, they were telling me I am a bad mother. My father told me forward [straight out] I am a bad mother. That I'm not doing enough to assist my child, umm, he is not, he can (.) I don't know what I am doing with him, umm, (.) I've been told that I need to, basically, that I need to do more for him. (P10)

It is hard because the, the family members like his aunt, his uncle, they doesn't understand what is going on. They said, "You are the one who makes _____ to be like this." (P3)

The people I work with and my family they understand but other people, I walk in the street and I go into the shops and _____ is shouting, not because he is throwing a tantrum but that is how he is. And I know he is not throwing a tantrum and people will look at you. (P7)

The above reports of negative and blaming responses from others are similar findings to other studies, suggesting that parents often struggle as they begin to deal with the perceived blame for their children's disability from other family members and society in general (Osborne & Reed, 2008; Siegel, 1997).

Mothers' emotional responses to diagnosis. It is not easy for a parent to receive a diagnosis of autism for their child, as they realise that their parenthood journey will be different from what they had hoped for. Participants in this study indicated that they moved through a grief-like process in response to the loss of a child that they had expected to have. Similarly to the parents in Boushey's study (2001), the participants reported that they experienced varied responses including shock, denial, anger and acceptance.

I actually broke down into tears; I became so emotional about it because you come to this realisation that (.) there is a possibility that your child is not going to be a normal child. (P2)

I just thought to myself, my kid is never going to grow up to have a normal life, normal school friends and you know girlfriends (...) I was actually just gutted. I sort of fell apart. (P6)

I was very shocked because I didn't know what autism was even (...) even now I am still shocked. I just want _____ to be the same like me. But I can't, so I pray to God that He must change him to be like me. (P5)

The last quotation suggests that the participants' responses were further complicated by the realisation that autism is a life-long condition that cannot be cured, which appears to have been overwhelming. The mothers thus only hoped and prayed for a miracle that would change their child.

The participants indicated that they also experienced and directed anger both towards close family members and the child. Their anger emerged in different ways– beating, screaming and yelling at and resentment of the affected child, as well as snapping, shouting and overreacting in relation to spouses and other family members:

I've put up with all this nonsense that he dishes out, I put up with it, (...) sometimes you just want to choke him. (P2)

Sometimes I was upset and saying things I don't like, I was saying things I regret after that. Like, I wanted to show anger to his father. (P3)

I actually felt like killing this child, that's how I felt, I felt like throwing him against the wall because he was trying, I didn't know what was going on. (P7)

The feelings of shock, denial, and anger reflected above are similar to Boushey's description (2001) of the stages that mothers go through when their children are diagnosed with autism. Although it was expressed as difficult to achieve, participants indicated that they had to reach a level of acceptance of their child's diagnosis in order to access the necessary support for him.

After like a couple of weeks we realised, you know, that we need to get out of this rut and we need to start doing something about the condition even though it's not curable, its treatable. So let's try and get him help and find therapists. (P1)

He will have a normal life but it's not that he is autistic; he will not have it for all his life. But we can at least get him you know ((support)), but if she ((her mother)) doesn't want to accept (.)((What)) worries me is that she won't do anything about it and if you don't accept it I think then he can deteriorate. (P6)

Well, I thought that if this is it, we have to obviously sort out getting means and ways to help him. (P10)

Similarly to Sinclair's (1993) findings, the participants reported that they had to change the focus from the child's autism to what needed to be done in order to cope with the situation, such as searching for necessary specialised treatments, securing day care facilities and making adjustments in the family system to cater for the child's expert care.

Impact of Autism on the Family System

Relationships with the non-affected children. Those participants in the study with a typically developing child/children reported that they struggled with maintaining a balance between the needs of the child with autism and their siblings. They reported that the birth of a child with autism affects relationships with their other children, mentioning for example, that they spend more time with the child with autism than they do with the non-affected children. Participants expressed concerns about the need to spend more time with the siblings. Some of these participants reported that this has created feelings of guilt and shame that they struggled with daily.

I feel I give _____ more attention than I am giving his older brother. Sometimes I feel like I am neglecting him because I must, because everything that is done is around _____. We need to spend more time with the other child as well, that's important. (P10)

You know because he ((referring to typically growing child)) knows he is not going to get any attention from me until _____ is sorted out. It's almost like (...) I know it sounds terrible, it sounds like I am neglecting my second child for the first, but there is just no way. (P6)

The above suggests that parental relationships with typically developing children are affected because of the attention needed to manage the child with autism. As a result, participants struggle with feelings of guilt and shame related to the neglect of their other children, and most reported attempting to balance this by making plans for how they could spend more time with the other sibling.

Changes in lifestyle. The participants reported that the diagnosis of autism had an impact on their careers. The majority stated that it was impossible to combine a full-time job with the care of the child with autism. This led to some of the participants feeling that they

were not helping their child financially and therefore not ensuring that they receive quality specialised intervention.

I can't go to work and bringing in the income so that we can afford extra therapies that make their lives easier. (P1)

Financially it's tough as well, but it's just the way I am, even though I think I need to go back to work - even part time just for some, you know, adult interaction, all I do is baby, baby, baby, you know, and it's not normal. (P6)

In the quotation above, it seems the mother felt the need to return to work as a way of re-defining herself and taking a break from caring for the child. It appears that the participants recognise that their lives centre around the needs of the child and feel as though they do not have time to themselves. However, some of the mothers reported that they did not make career changes to accommodate the “differentness” of their child with autism.

I have to run a normal life, I have to work, I have to get up in the morning. I have two other children to see to (...)

In addition to employment changes the participants in this study mentioned that they had to make adjustments to daily activities such as shopping, eating out, family gatherings and holidays. They indicated that they were no longer spontaneous and able to engage in activities that they had not planned for.

He can't go on the escalators because he starts hitting himself. So what you do, you just don't take him to shopping centres instead and prevent those situations. Prevent them if you can, if you know what triggers them off, rather just don't go there. (P2)

But we've had to change quite a bit of our lifestyle, we used to eat out often, we used to go and socialise with friends, we used to go out in groups, but now our whole lives revolve around the security of our sons, and what's going to make them comfortable, what's going to be too overwhelming for them, so, umm, a lot has changed. (P1)

I resigned from work last year March/April and I've been at home since then and we haven't gone on a holiday. (P10)

The aforementioned disruptions to family life have been well documented by studies focused on the day-to-day impact of a child with autism on the entire family system (Altieri & von Kluge, 2009; Davis & Carter, 2008; Meyer et al., 2011; Nadon et al., 2011). Some of the

mothers in this study were mindful of the need to construct normalcy for their child and to integrate him within the family. For example:

Yeah, it's a normal life I have to live, it's not because I have a child that's autistic the world has to come to an end, I have to run a normal life. I have three other children to see to (...) two other children, so you make it as normal as possible. (P10)

I mean we treated ___ the same way even up until today (...) we treated him as normal you know, and he understands us so well, ((laughs)) he is so cute. (P9)

Amidst the difficulties that a child with autism posed to participants, it appears that some mothers treated the child's diagnosis as an obstacle that they could overcome. They made meaning of their experience and worked towards constructing normalcy in the family life in order to deal with the presence of a child with autism within the family.

My Greatest joy, my Greatest Heartache

While the challenges described in the previous sections are pertinent, and should not be ignored, it also emerged that there were some positive outcomes in raising a child with autism. All the mothers in this study described a positive learning experience when asked to reflect on their motherhood journey with the affected child. Similar to Kayfitz et al.'s (2010) finding that higher levels of caring for children with intellectual disabilities also contributed to reports of more personal growth and maturity in the women, the participants in this study also stated that there were some gains from their experiences:

I think it has made me a much, much more conscientious mother, I don't think (.) if my kids were normal I would have left them anywhere ((laughing)) and I wouldn't have as much concern and care (...) it's just added value to my life. (P1)

I have learnt not to judge parents. You learn patience, you learn to not ((pause)), if something goes wrong not to always make it right immediately, not to always scream, but you actually learn to step back and walk away and come back again in an hour's time. (P10)

Having this child has taught me so much patience and compassion and understanding more, take the time rather than to just throw you hands in the air. (P2)

Amidst the demands and stress a child with autism may have on mothers, participants reported that the child brought positive contributions to their lives. The participants thus

described personal benefits that would have not occurred without the presence of their child. There were, however, concerns about the future, as will be discussed below.

Uncertainty about the Future of their Child

The delay and problems with obtaining a formal diagnosis for a child with autism presented earlier were not the only challenge that the participants experienced in obtaining appropriate support for their child. The Western Cape has a well developed network of special schools and forms of education for learners with various kinds of disabilities (Autism South Africa, 2000); however, educational facilities for children with autism are limited. The participants in this study provided some insight into the dissatisfaction with the supply of appropriate services and schools for children with autism, with particular reference to the accessibility of day care centres and primary schools for their children. They spoke about a long journey that they had to go through to obtain placement for their child, with some mothers still awaiting a response.

So when they said he's autistic (...) and that's the problem now (.), is getting him to schools, there's two year (...) three years waiting period in schools like Vera and Alpha schools – there's not many schools in the Western Cape. (P10)

We were lost, in a way, where we didn't know where we were going to take him to day-care (...) that was the frustrating part, where I noticed that in the Western Cape there was only about one or two schools that has autistic, (...) autism, for autistic children. And we've been basically everywhere in _____ and they keep referring us to and fro. (P9)

He went for a school that he is on the waiting list for (...) and told me they will call in eighteen months time; whether eighteen months time before he goes for an assessment for two weeks, then they will tell me whether he can or cannot attend the school. Now what happens to him in eighteen months, you know, what do I do with him in eighteen months? (P10)

Most of the participants reported some challenge related to schooling for their child, with only one child being enrolled in a specialised school for autism while two were reported to be at schools that cater for general disabilities. Six of the participants stated that their children were still awaiting placement at day-care and pre-school facilities. They indicated

that they had to wait between 18 and 36 months to get feedback from the schools. However, one participant indicated that even the existing services do not cater for all children, leaving out those that do not fall within the bracket of “autistic”:

He doesn't fall in the bracket where ____ school and ____ school where there is children with autism that can talk, walk etc. ____ is not on that level so he is not accepted. (P7)

The participants' reports suggest that there is a limited number of schools available in Cape Town to meet the high demand of children with autism, consequently schools face an enormous backlog of waiting lists of children in need of help. Participants therefore found themselves having to endure long waits for their child to be placed in a school.

In addition, after their child receives a diagnosis of autism, parents recognise that their child may not have a future that most healthy children will have such as a carefree childhood, university studies and marriage (Altiere & von Kluge, 2009). The participants' realisation that their child will not lead a normal life contributed to anxiety about the future (Ogston, Mackintosh & Myers, 2011).

I am terrified by about what is going to happen when myself and my husband is not here anymore. I can't sleep at night because that's like my concern all the time because I don't have any family that would financially be able to look after two kids with autism. (P1)

He will never have a normal life, because how will he ever be able to study further after school if he is going to a school with autistic children? And how will he ever be able to get a job and have a normal life? (P2)

My main concern is what happens to him when I'm not around anymore, my main concern is will he be able to cope in society, my main concern is whether he's going to be happy, is he going to get married, is he going to have children, is he going to be able to have a normal job? (P10)

It appears that participants initially envisaged a future for their child that involves marital relationships, child bearing, social relationship and occupations. However, upon finding out about their child's condition, they were preoccupied with thoughts of uncertainty.

Conclusion

The aim of the study was to explore the experiences of mothers raising children with autism and how they adjusted in different areas of family life following a diagnosis. This aim was accomplished by conducting semi-structured interviews with ten mothers in Western Cape. Themes and sub-themes were identified through thematic analysis of the transcriptions.

The findings of the study reflect that parental distress began in the pre-diagnostic phase when mothers noticed developmental delays in the children. Participants became anxious and worried when the child did not develop speech, and behavioural problems became difficult to manage. Participants reported struggling to reconcile the child's atypical development with the normality of his appearance. This sense of confusion may help to explain why parents do not immediately discuss their concerns with their paediatrician or other professionals and, instead, utilise other sources such as the internet and television programmes to inform their observations (Glazzard & Overall, 2012). However, when they did consult professionals, participants reported that initial contact with health professionals was not particularly helpful. The relationship between helping professionals and parents is important as it is this initial support that the latter use through the diagnosis process (Ahern, 2000).

The participants in this study were dissatisfied with immediate helping professionals, such as paediatricians and nurses, because they felt their concerns about the child's development were dealt with in a dismissive manner and that contradicting explanations of the child's unusual behaviour tended to be assigned. As a result, the participants felt helpless and disempowered in initiating efforts to assist their child. The situation where the participants did not know what was wrong and could not get clear answers from health practitioners led the parents to feel unsupported and experienced feelings of self-blame.

This may partly be due to what Avdi, Griffin and Brough (2000) argue are mothers' tendencies to take credit for their children's progress and development because it is linked to maternal competence, which therefore means that slow development reflects maternal failures. The findings from this study therefore suggest that professionals need to engage more with families when giving a diagnosis of autism, particularly with families from low socio-economic backgrounds, whose understanding of the disorder may be minimal. This implies that it is important for health professionals to provide informational support and guidance for mothers during the pre-diagnostic process to empower and help them understand how they can manage the disorder.

Receiving a diagnosis of autism has been described as uniquely stressful and emotionally intense, with parents in this study reporting that they experienced feelings ranging from the relief that their suspicions were validated, to grief over the loss of the life

they imagined for themselves and their child; responses that have been found in other studies (e.g. Avdi et al., 2000; Osborne & Reed, 2008; Siegel, 1997). Thus, the participants' initial feelings of relief at having a label to explain their children's unusual behaviours and development were later replaced by a sense of despair and devastation at the recognition that the child would always have special needs that typically developing children do not. Interestingly, feelings of anger were externally directed to God and spouses, as well as internally towards themselves.

Although described as normal reactions to a diagnosis of a pervasive developmental problem like autism, the findings strongly suggest that early interventions are crucial, not only for the affected child, but also for parents, in order to prevent a potentially destructive build-up of anger which may lead to depression or possible abuse of the child. This is especially pertinent to the South African context where children with disabilities could potentially be exposed to various forms of abuse. However, although participants found the process difficult, they reported that acceptance could be achieved once they had thought about and come to terms with the implications of their child's condition and the realisation that they needed to search for and activate the care for the child's special needs.

What emerged from this study is that families of children with autism experience high levels of stress and often have to make adjustments that affect their careers, finances and lifestyles. In addition, the findings show that the autism disorder impacted all family relationships, including parental ones with non-affected children in the family. Such a discomfiting recognition of engaging differently with non-autistic children has been reported in other studies (Boushey, 2001; Ogston et al., 2011; Nadon et al., 2011; Roth, 2001) where participants felt that they were neglecting their other child/children because of the emotional and time demands required for the one with autism. The perceived lack of their availability to their other children further contributed to feelings of guilt and shame in the participants. Therefore, special attention needs to be given to parent-child relationships within the family to avoid harboured feelings of resentment and rivalry towards the child with autism which may affect the sibling relationship, as well as to nurture a mother-child bond for all children. As indicated in previous research, this is also important as siblings of children with autism disorder tend to exhibit higher levels of adjustment problems (Meyer et al., 2011).

In relation to challenges with which they were confronted, the participants reported that they were highly dissatisfied with the state of the current educational facilities for children with autism. The main concerns related to the long waits for assessments, admission

criteria and the number of day care and primary schools available in Cape Town. Autism South Africa (2000) suggests that there are insufficient facilities for children with autism nationally, with Cape Town having three of the nine autism-specific schools, with the rest located in Johannesburg, Pretoria and Durban (Autism South Africa, 2000). In addition to the lack of facilities, participants indicated that they would appreciate having more information regarding a range of inexpensive interventions and educational programmes available for their children. In the economic situation of South Africa, the participants had minimal financial capabilities to provide private school education for their children. Therefore, the findings suggest that mothers raising children with autism may benefit from professionally run support groups where they can be provided with informational support on how they can educate or assist their child while in the process of awaiting for a school placement.

As all parents face great responsibility in making plans for the future of their children, this responsibility seemed heightened for participants in relation to their child with autism. It therefore placed pressure on these parents to initiate greater efforts in ensuring that their children's needs would be addressed when they were no longer capable or present to care for the child. The participants considered various options such as relocating to cities such as Johannesburg to secure future facilities like retirement homes where the needs of children with autism are accommodated. It can thus be said that autism has emotional, financial and practical implications on families.

Despite the challenges mentioned, some participants mentioned that although the child posed unique challenges, it was important for them to construct a normal life, and that there were positive aspects to the experience, notably enhanced personal characteristics such as patience, compassion, and acceptance, especially of others with disabilities. The mothers emphasised the personal growth and maturity that their motherhood journey with a child with autism has brought. The above findings are consistent with the view of Ekas and Whitman (2010) that mothers can focus more on the positive attributes of the child and take an optimistic stance on their experience to help them successfully manage and respond to the challenges linked to the child's autism. The participants mentioned that their children were their greatest source of joy and have provided meaning to their lives. Therefore, this study suggests that although children with autism pose challenges for mothers, it is possible to find coping mechanisms to overcome daily challenges. The findings from this study therefore provide hope and encouragement for parents of children with autism in particular, but also for parents raising children with intellectual disabilities in general.

In light of the limited scope of the study, the researcher could not explore the support structures that mothers utilise daily to cope with their experience and therefore future studies may yield interesting findings in this regard. Additionally, future research may focus on understanding how society views mothers and families of children with autism as this may have a significant effect on the mother's reaction to raising a child with autism.

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Appendices

Appendix A: Interview Schedule

Appendix B: Informed Consent Form

Appendix C: Referral sheet

Appendix D: Key on the transcription system

Appendix A: Interview Protocol

Interview Protocol Project: The Lived Experience of Mothers Raising Children With autism

Time of interview:

Date:

Interviewer:

Interviewee:

Questions

1. What were your experiences of the pre- diagnosis phase?
2. What are the key problem areas after diagnosis?
3. What are the negative and positive aspects of raising a child with autism?
4. What are your concerns regarding the needs of your child?
5. What health facilities are in place to assist you
6. In your opinion, how do you think your needs as a mother of a child with autism can be better understood?

Appendix B: Participant Consent Form

UNIVERSITY OF CAPE TOWN



Department of Psychology

University of Cape Town Rondebosch 7701 South Africa

Telephone (021) 650 9111

Fax No. (021) 650 4104

Dear Parent

I hereby request your participation in a research project that aims to explore the experiences of mothers raising children with autism. This includes experiences before the diagnosis of autism, the experience of the diagnostic process and how mothers adjust and learn to cope after an autism diagnosis, and as well as their primary needs and concerns of raising a child with autism. The information provided by you may help health professionals to better understand the experiences of parenting a child with an autism disorder and ways to address the needs of mothers.

Your participation will involve one 60-minute interview conducted either at the Child Guidance Clinic or your home. In this interview the researcher will ask questions that relate to your experiences of raising a child with autism.

Potential risks and benefits

It is possible that your participation in this study may elicit mild psychological distress related to the disclosure of information of a personal, and potentially difficult, nature. You may experience some sadness or other feelings, that you might prefer to avoid, as you describe your journey with your child to me. Although this may be the case, most people find it helpful to tell their stories in this structured way.

If you feel distressed in any way, we can take a break, or you can decide not to go on with the interview. If you experience psychological distress that is intolerable or beyond what you expect, you may choose to use the referral resources provided. There will be no direct benefit to you from participating in this study; however, you will be reimbursed for any transportation costs that you incur in your participation.

Termination of research study

You are free to choose whether or not you would like to participate in this study. Deciding not to participate will not affect any services that you or your child receives at the Child Guidance Clinic in any way. Please also note that you have the right to withdraw from this research project at any time. The researcher will provide you with any significant new findings developed during the course of this study that may relate to or influence your willingness to continue participation.

Confidentiality

Your identity in this study is completely confidential. All identifying information will be kept in separate locked cabinets which are only accessible by the researcher. Once the researcher has transcribed the interviews, she will provide a pseudonym for real names of participants and any tape recordings will be destroyed upon completion of the study. The results of the study, including any other data published, will not include your name or include any identifiable references to you.

Please refer any further questions you have about this study to the following:

Principal researcher: BatetshiMatenge

Phone Number: 0767793077

Supervisor: Dr NokuthulaShabala

Phone number: 021 650 3435

Secretary for Ethics Committee: Rosalind Adams

Phone number: 021 650 3417

I have read and understand this consent form, and I understand that I will receive a copy of this form. I voluntarily choose to participate, but I understand that my consent does not take away any legal rights in the case of negligence or other legal fault of anyone who is involved in this study.

Participant Name:

Participant Signature:

Date:

Principal Investigator Signature:

Date:

I give consent for the audio of this interview to be recorded. I understand that the audio-recording is to accurately record the information that I provide, and will be used for transcription purposes only. If I feel uncomfortable at any time during the interview I may

request the researcher to turn off the audio-recorder. Or, if I do not wish to continue, I may ask the researcher to stop the interview at any time.

Participant Name:

Participant Signature:

Date:

Principal Investigator Signature:

Date:

Appendix C: Referral Sheet

Resource Information Sheet

As the interviews will require you to recount your experiences of raising your child with autism, this may elicit emotions that you may find difficult to deal with or you were unaware of. In the event that you experience high psychological distress or would like to process your experience in therapy, please feel free to contact any of the therapists provided below. They will avail themselves if ever you need support on issues raised as a result of your participation in the study.

NokuthulaShabalala

Clinical Psychologist
Child Guidance Clinic

021 650 3900

0828297960

NoleenSeris

Clinical Psychologist
Mowbray

0216892077

Kerri Delport

Project and Support Manager
Autism Western Cape

021 685 9581

Appendix D: Key on the Transcription System

- The symbol (. . .) indicates that some of the transcript has been deliberately omitted.
- Material in round brackets (()) is the transcriber's descriptions.
- A small gap or pause between utterances is indicated by (.)
- The two numbers in brackets at the end of quotes refer to the participant's interview number respectively.
- Non-verbal information, such as laughs and pauses are indicated as (laughs) respectively. No other non-verbal information was recorded.