

Common Stressors that Parents of Children with Autism Face in Saudi Arabia

Lama Sahab* Reem balubaid,2

- 1. Specialized in Psychology, Saudi Arabia
- 2. Specialized in Education, Saudi Arabia
- * E-mail of the corresponding author: lama.sahab@gmail.com

The research is financed by Asian Development Bank. No. 2006-A171(Sponsoring information)

Abstract

Autism is a neurological disorder that causes a number of challenging cognitive and behavioural impairments. These include delays in learning and self-sufficiency, as well as repetitive and obsessive behaviours. Children with autism are more prone to mood swings and insomnia and the disorder is often comorbid with other behavioural disorders as well. Parents of children with autism can understandably experience high levels of stress when raising their children and can often feel guilty for their child's condition. Understanding how parents cope with disability is important for reducing stress in these family units and ensuring disabled individuals receive the support they need.

Although public services are relatively developed in the first world, Saudi Arabia is still considered to be a developing country and unfortunately, the disorder remains relatively unknown (Alqahtani, 2012). A lack of awareness means that members of society are more likely to ostracise families of autistic children, which may discourage these families from engaging in normal activities and further increasing their stress. The present research used a qualitative design to gather data from nine parents of children with autism in Saudi Arabia. The interviews were transcribed and then analysed thematically.

The analysis identified six themes, namely, a lack of social awareness about autism in society; a lack of services for children with autism; problems with sleep; a lack of professional diagnosticians; care as all-consuming and finally, the lack of support available and its importance for coping. The paper finds that parental stress is caused by a lack of professional support and social understanding although the causes and implications of parental stress in autism is a broad topic with considerable implications. As such, there remains a need for further research, particularly in countries where understanding is limited, such as in Saudi Arabia.

Keywords: Autism, stress, parents, children, Saudi Arabia, qualitative study

1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects social communication and social interaction in many spheres of life (Kim et al., 2014). Indications of autism include impaired abilities in the intrapersonal and emotional reciprocity, deficits in nonverbal interaction for the purpose of socialisation and a lack of building, sustaining, and understanding relationships. In addition, children with autism usually develop repetitive and limited patterns of behaviour, activities and hobbies (Kim et al., 2014).

A recent study in the UK considered the changing prevalence rates of autism over time and found that, while there was a sharp increase during the 1990s, prevalence rates were stable in the early 2000s and remained constant through to 2010, at a rate of 3.8 per 1000 for boys and 0.8 per 1000 for girls (Taylor, Jick, & MacLaughlin, 2013). This is in significant contrast to estimates made by the Center for Disease Control in the United States (during 2011-12), which found the prevalence of autism among children aged 6–17 years to be one in 50 (Blumberg et al., 2013). There are no official statistics for the prevalence of autism in Saudi Arabia. Alqahtani (2012) suggests there were 40,000 confirmed cases in 2002 and the study by El-Tarras, Awad, Mitwaly, Alsulaimani and Said (2012) suggests a rate of 18 out of every 10,000 children. The lack of awareness of ASD within this country overall however may be leading to significant underreporting (Alqahtani, 2012).

1.2 Study Questions

1. What are the teachers' perceptions of ICT implementation for students with ASD?



- 2. What are the teachers' perceptions of the main barriers to ICT implementation for students with ASD?
- 3. What are the teachers' perceptions of the measures needed to improve ICT implementation in mainstream schools?

2. Literature review

2.1 Autism and Parental Stress

Parents of children with autism are often required to make significant changes to their family home and living arrangements (Kayfitz, Gragg, & Orr, 2010; Gray, 2002) and many of the behavioural traits associated with autism are particularly demanding (Dabrowska & Pisula, 2010). The demands made by autistic children are exacerbated by the fact that autism is often found to be comorbid with other challenging disorders as well, including attention deficit disorder (ADD) and mood swings (Baron-Cohen, 2004). It is therefore understandable that parents of children diagnosed with autism experience elevated levels of stress.

Some have suggested parental stress is due to the sense of responsibility they feel for their child's illness (Blackledge & Hayes, 2006) although others have identified the problematic behaviours as the key variable (Schieve, Blumberg, Rice, Visser & Boyle, 2007). This was confirmed by the study by Nachshen, Woodford and Minnes (2003), which found that parents of children with more serious behaviours experienced higher levels of stress than those who merely had mild to moderate maladaptive behaviours (Hastings, 2003).

Since autism is a permanent condition, challenging situations for parents on a daily basis can lead to chronic stress. Research suggests that parents of children with autism are more likely to suffer from chronic stress than parents of children with other disabilities (Dunn, Burbine, Bowers & Tantleff, 2001; Weiss, 2002) including Down syndrome or cerebral palsy (Smith, Hong, Selzter, Greenberg, Almeida & Bishop, 2010). Ensuring mothers are able to implement coping strategies successfully is therefore important to the well-being of the parent as well as the child.

2.2 Elevated Stress for Parents of Children with Autism

The study by Dabrowska and Pisula (2010) found that parents of children with a developmental disability often experience from higher levels of stress than parents of a typically developing child and parents of children with autism are more likely to demonstrate depression and anxiety symptoms (Yamada et al., 2007).

Smith et al. (2010) asked mothers of children and adolescents with ASD to keep a record of their experience for eight days. Mothers of children with ASD were found to spend less time on social activities and more time on housework and providing care than mothers of typically developing children. These mothers also reported higher levels of stress and exhaustion, as well as family disputes but they also suggested they did experience some more positive interactions as well.

2.3 Severity of Autistic Behaviour

The study by Ingersoll and Hambrick (2011) used a survey to examine ASD, stress and depression in nearly 150 parents of children with ASD. It found that high levels of stress and depression were correlated with the severity of the ASD symptoms and also highlighted the ability of social support networks to mediate stress caused by challenging behaviours.

2.4 Age and Experience

Studies have examined whether parents experience greatest stress when their child is in infancy or adolescence because while a child may develop greater needs as they get older, they may also be less likely to engage in challenging behaviours. Barker et al. (2011) studied nearly 400 mothers of children with ASD and investigated the incidence of depression and anxiety over a ten year period. While older mothers experienced less depression and anxiety than younger mothers, symptoms of depression were found not to change throughout the ten year period. Levels of anxiety did however reduce over time. The methodology used in this study was self-reporting and it is possible that this affected the results through, for example, under-reporting of personal problems. The study by Singer (2006) included a meta-analysis of cross-sectional research and found that depression was higher among mothers with younger rather than older children.

Smith, Seltzer, Tager-Flusberg, Greenberg and Carter (2008) conducted comparative longitudinal research into mothers of children with ASD and discovered that mothers with younger children experienced less emotion-focused coping and more problem-focused coping. When considering mothers of adolescents with ASD, it was found that coping responses mediated their levels of stress although they did experience significant levels of anger. Smith et al. (2008) suspected this may have been made worse by the problems that families with



adolescents experience anyway. Overall, both groups of mothers experienced significant distress and one in three mothers had higher than average levels of depression.

The study by Lounds, Seltzer, Greenberg and Shattuck (2007) suggested that levels of anxiety reduce overtime for mothers of children with ASD between 13-22 years old. As such, it may be argued that parents learn to cope with the challenges presented by ASD over time and this makes it even more important to investigate those techniques that are effective in improving parental well-being. Improvements in challenging behaviour can go some way to relieving the practical and psychological difficulties associated with the disorder.

2.5 Maternal and Paternal Stress

Some research has suggested that mothers of children with autism report higher levels of stress than fathers and it has been speculated that this is due to the differential degrees of involvement in childcare (Yamada et al., 2007). As found by Gray (2003), mothers were often more directly affected by the child's disorder, whereas fathers reported experiencing stress due to the impacts of the disorder on their spouse.

In their study of pre-school children with cognitive impairments, Hastings, Beck and Hill (2005) found that mothers experience more positive interactions with their autistic children than fathers and were better able to adjust to the demands. Mothers also reported greater social support, as well as a heightened sensitivity to family matters and compassion towards others with disabilities. Fathers were more likely to suggest they were proud of their autistic child and identify behaviours of the child that helped with the housework.

Rivers and Stoneman (2003) have pointed out that many studies on parental stress have not considered the way in which mothers and fathers play different roles and as such, this variable is often not properly distinguished in many studies. It is also possible that parents may feel inclined to give answers that reflect what is considered socially acceptable.

The study by Tehee, Honan and Hevey (2009) administered questionnaires and found that mothers experience greater levels of stress than fathers, although the stress was mediated by factors including the child's age, support available, the quality of the support, as well as the availability of suitable information about the disorder. Their research also found that parents of children with more severe behavioural symptoms more likely to feel pessimistic and this often meant coping strategies were less effective.

2.6 Siblings

Rivers and Stoneman (2003) investigated dynamics between siblings where one of the children has autism. They found that families with typically developing siblings and an autistic child could result in compromised and negative sibling relationships that contribute to parental stress and affect the marital relationship. Although marital stress was mediated by informal social support, there was not a similar mediating effect on negative sibling relationships. Families who experienced high marital stress and negative sibling relationships were more likely to seek external professional support (Rivers and Stoneman, 2003). In this respect however, Rivers and Stoneman (2003) note that academic material regarding sibling relationships is currently inconclusive and there have been mixed findings to date.

2.7 Coping Strategies

The study by Pottie and Ingram (2008) asked parents to keep diary of the stressful events they experienced on a day-to-day basis and record the actions they took in response. They were also asked to indicate how they were feeling by the end of the day. The study identified five main coping techniques. Support from other parties and positive reframing resulted in an increase in positive mood, whereas escape and withdrawal often led to a decrease in positive mood. The study also identified that various factors can moderate coping responses; including emotional regulation and levels of support. The severity of the ASD and the gender of the individual however did not predict parental mood.

Tehee, Honan and Hevey (2009) also found that if parents felt confident about the usefulness of coping strategy, they were less likely to experience pessimism and this suggests it is important to consider the personalities of the parents when determining which intervention strategy will be most effective. The study suggested that intervention must occur at the correct time and support should be flexible to meet the family's needs (Tehee, Honan and Hevey, 2009).

2.8 Conclusion

The literature has identified a number of variables that can increase parental stress when a child has autism. The aim of the present research is to identify the main causes of stress for parents of children with autism and identify the techniques that can help them cope.



3. Methodology

3.1 Methodological approach

Studies in this field have adopted various methodological approaches. For example, the study conducted by Nachshen, Woodford and Minnes (2003) used both qualitative and quantitative measures, including a checklist to gather demographic data, interviews to collect qualitative responses as well as the Vineland Adaptive Behaviour Scales—Maladaptive Behaviour Domain (VABS-MBD) (Sparrow & Cicchetti, 1985).

The present study sought to collect qualitative data from parents regarding their experiences within the relativist and interpretivist paradigms. These paradigms look to the individual and the environment in which they operate to obtain an accurate understanding of their personal experiences (Robson, 2002). This approach will be important in the present study because of the emphasis on the individual experience of the participant. Rather than seeking objectivity through data from a large sample, the present study requires depth into the personal experiences of the participants and for this reason, a quantitative design is considered unsuitable for the present study.

Because of the subjective nature of qualitative designs, it is important that the responses of participants are not unduly influenced by the opinions or attitudes of the researcher and as such, methodology must be suitably rigorous (Silverman, 2010). Indeed, qualitative studies have often been criticised for lacking reliability and the present researcher is aware of the need to design a study that is sufficiently robust.

3.2 Sampling

3.2.1 Participant Characteristics

Sampling techniques often used in qualitative designs include purposive and convenience sampling (Denscombe, 2003; Silverman, 2010). Purposive sampling describes the process whereby a researcher targets participants who are considered the most suitable for examining a particular hypothesis. In the present study, purposive sampling has been selected for pragmatic reasons.

The present study will include nine parents of children with a clinical diagnosis of either autism or ASD. All the participants lived in Saudi Arabia although some were of different nationalities. It was considered most appropriate to interview non-disabled adults for ethical reasons because this meant they could be sure to have given their consent. Apart from consent, no major ethical issues arose in this study. Both men and women took part in the study and there were no exclusion criteria. One of the participants included the founder of *Mummy Cares*, an informal support network for parents of children with autism in Jeddah, Saudi Arabia.

3.2.2 Participant Recruitment

Recruitment was carried out through the Jeddah Autism Centre, which is an official centre for families in this region, as well as the local support group, Mummy Cares. Participants were also contacted through word-of-mouth, as well as through direct advertising. This included posting informational notices at the centres. The participants who responded were provided with further information and also asked to complete the consent form. All the material was written in English.

3.3 Data Collection Methods

The present study used semi structured interviews to collect data and included a list of prompts (see Appendix B). These were used to direct the discussion and provide the participants with greater scope to express their views (Holloway & Fullbrook, 2001). The interviews were first piloted on a test group to ensure the language was easy for the participants to understand. Piloting also provides a good opportunity for researchers to practice their interviewing skills (Briggs, 2007). The interview was designed to take approximately one hour and the participants were able to choose the location for the interview (including a private room at either the Jeddah Autism Centre, Mummy Cares, or the participant's own home) helping the study to ensure privacy and confidentiality. The interviews were conducted in English, recorded with a Dictaphone and then transcribed into text. The transcriptions were sent back to the participants for member-checking, to enhance the validity and reliability of the findings (Fontana & Frey, 2005).

4. Results

The study identified six main themes as a result of the qualitative interviews. These included: a lack of social awareness about autism in society; a lack of services for children with autism; problems with sleeping, a lack of professional diagnosticians, care as all-consuming and finally, the lack of support and its importance for coping.

Lack of Social Awareness about Autism in Society

Nearly all of the participants identified there was a lack of awareness in society about autism. They suggested



this could be particularly stressful when children exhibited problematic behaviours in public and possibly attracted attention and criticism, for example one parent said "It is difficult for the parent especially when going to public places where people do not understand what's wrong with him".

Children with autism cannot simply be kept at home all the time so public excursions are therefore often an unavoidable challenge, which makes it extremely difficult for the parents to go out with their child as one father stated" The other thing is when you go out, some families and the society in general a lot of them they do not know what is autism so you might face embarrassment going to a restaurant or to the mall."

Lack of Services for Children with Autism\

A majority of the parents identified that are currently too few services available for children with autism in Saudi Arabia and that this can increase parental stress. Parents may for example be faced with long waiting lists in order to enrol in specialist centres 'It was challenging to find a school for him because there was only one centre with a huge waiting list and whether you like it or not this is what you get, whether you like the school or not this the only school available so you have to put him there'. Other parents experienced challenges as centres were unable or unwilling to meet their requirements, including failing to create a tailored plan of support. Parents were faced with having to send their child abroad because no local centres were prepared to accept them. Many of the centres that were available did not provide support for the full duration of the school day: 'Finding a school was not a problem in the states but when we came here, JISH is the best and it is very good but it is not a school where he goes from 8 till 4 like the states, it is a problem and schools and centers are problem her because you cant find any services there are nothing available seriously nothing and we keep talking about sending our children abroad because here they do not get the full hours they nee'.. These factors put additional pressure on parents.

Lack of Professional Diagnosticians

Just over half of the participants suggested they experienced stress because there were not enough professionals able to diagnose autism, such as 'We started with the challenge of someone actually knowing what is autism and how to diagnose, we went to many doctors and each doctor told us maybe he is this or this and finally we found someone who told us MAYBE he is autistic'.. Diagnosis is often the first stage that families go through and points the direction to the next appropriate sources of support. A delay in diagnosis often leads to increased feelings of stress as parents remain unaware of the cause of their child's problems and consequently do not know how to respond. Parents often had to rely on online sources and some even had to take their child abroad, in order for the initial diagnosis to be made (including to Europe and the United States).

Dealing with Sleeping Problems

Four out of the nine participants identified that disturbances with their child's sleep was particularly problematic and could affect their child's behaviour and performance at school. In one case, this meant a child had to be taken out of their speech therapy class. Another parent said the main problem lay in the behaviours their child demonstrated upon waking up: 'he sleeps only two or three hours at night and he is not like the kind of children you can leave alone and do something or put him in front of the computer or TV, everything with him will be on the floor'

Care as All-Consuming

Six out of nine participants said that caring for a child with ASD is extremely exhausting. It can serve to overshadow the parents' social life and some parents had to give up on plans such as traveling, working or completing the education, for example 'It's very stressful, it's very hard, and it's very difficult. It runs your life. It decides what you do in your life ... how much I can work depends on my son, which is not much. I work a little. How much I can go out, my social life, everything is affected. It affects the family, the siblings, absolutely everything'.

Lack of Support and its Importance for Coping

Mummy Cares is a social support group for mothers of children with autism in Jeddah, Saudi Arabia. The group provides mothers with a forum to discuss common issues that they face and share their experiences although unfortunately, social support groups are not widespread or well-known in the KSA. Five of the nine participants said talking with other parents in a similar position helped them to cope and seven out of the nine participants identified their relatives as their most significant source of support: 'My husband is a big support, support to whatever we need to do to the family to the child or to myself, that's a huge help, I am not fighting against him. The kids try to help with my son and try to be good role models when I want them to be. There are times when they are wild and unhelpful'. Some of the parents admitted however that they were still finding it difficult to cope with their child's disorder



5. Discussion

The present study identified a number of stressors faced by parents of children with autism, as well as the some of the strategies that help them cope with those challenges. Coping strategies are important because they enable parents to deal with behaviour that may otherwise be considered anti-social and can help these families live as normal a life as possible. Understanding parental stress is a key variable in ensuring the well-being of an autistic child, due to the major influence of the caregiver on the child's development (Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005).

Thematic analysis of the data was able to identify six main themes regarding parental stress. These included: 1) a lack of social awareness about autism in society; 2) a lack of services for children with autism; 3) dealing with the child's sleeping problems; 4) a lack of professional diagnosticians; 5) care as all-consuming and 6) the lack of support and its importance for coping.

Lack of Social Awareness about Autism in Society

As was demonstrated by the present study, being out in public with a child who has autism can cause family members to feel marginalised. This was examined by Gray (2008), whose qualitative analysis demonstrated that autism is particularly susceptible to stigma and this can also contribute significantly to parental stress. An uninformed public may question the child's unusual behaviour and may not consider it is due to a disability. Indeed, the autism disability is not identified by any external physical differences to other children. Gray's (2008) study suggested that mothers are more likely to avoid ordinary activities with their child because of the stress caused by the stigma. Much of the existing research into social awareness is based on the individual opinions of the parent themselves and the extent to which this genuinely reflects public sentiment could be an avenue for further research.

Lack of Services for Children with Autism

Caring for a child with autism is significantly more challenging than caring for a typically developing child and for this reason, the provision and availability of appropriate professional services can be of critical importance. Gray (2002) reported that the lack of specialised support can be a significant source of stress for parents. This is particularly problematic in Saudi Arabia because there is not a sufficient number of qualified caregivers and diagnosticians available to meet the incidence of autism in the population. According to Alqahtani (2012), some children are receiving only a quarter of the therapy sessions they need. Parents are often forced to fund their childcare privately, which can also add to the experience of chronic stress and depression.

Dealing with Sleeping Problems

Poor sleep patterns can mean that the child as well as other family members have their ordinary routines disrupted. Sleep disorders are common in children with autism can be a significant cause of stress, anxiety and depression (Williams et al., 2004) and most families affected by sleep disorders require additional assistance (Mandell & Salzer, 2007). Sleep disorders can make existing behavioural challenges worse as children are more likely to be hyperactive and aggressive (Williams et al., 2004). Autistic children with sleep disorders are also less self-sufficient and are more likely to engage in self-harm (Krakowiak et al., 2008).

Therefore, whilst the sleep problems in a child with autism are extremely disruptive in themselves, the associated problems with the sleep deprivation also contribute to the parent's experience of chronic stress. In addition, Krakowiak et al. (2008) recognised that disruptive sleep patterns prevalent in children with autism is also detrimental to their confidence and self-esteem and heightens their social problems, putting them under significant levels of stress.

Lack of Professional Diagnosticians

Parents of children with autism are in particular need for advanced medical guidance at an early-stage because the disorder is both so unusual and demanding. As such, access to professional support can be a key factor in a family's ability to cope and early diagnosis can make a significant difference (Twoy et al., 2007). Participants in the present study often reported that the professionals they interacted with suffered from a lack of understanding about autism. They also reported a perceived lack of empathy on the part of those professionals, which led them to experience feelings of guilt and stress. Gray (2002) also reported that levels of stress decline from the point of diagnosis.

It has been recognised that there is a significant lack of appropriate diagnosticians in Saudi Arabia and this has been considered a consequence of the country still being part of the developing world (Al-Salehi, Al-Hifthy & Ghaziuddin, 2009). In their research, Al-Salehi et al. (2009) found that 25 out of 37 children were simply being medicated rather than being given therapeutic interventions.

Care as All-Consuming

While previous research suggested that parents feel their child's disability was all-consuming because of the perceived responsibilities they felt (Blackledge & Hayes, 2006), the present research did not identify the parental sense of responsibility as being a significant factor. According to the participants in the present study, the feeling of being overwhelmed was a factor that influenced their levels of stress.

Parents of children with autism also reported that the disability meant they were not able to do things that



families would otherwise enjoy. Woodgate et al. (2008, p. 1075) stated that parents of children with autism report, "feeling in a world of our own" as well as a degree of social isolation. In their earlier work, Schopler and Mesibov (1994) identified that mothers tended to perceive the disability as all-consuming more than fathers and suggested this could be due to them experiencing greater freedom as they are able to leave the house for work. The internet may now be providing mothers with greater options and this could therefore be a possible avenue for future research.

Lack of Support and its Importance for Coping

Research by Higgins et al, (2005) identified that one of the most effective coping strategies for parental stress is social support groups. Support groups were found to decrease psychological stress and help sustain healthy family and marital relationships. They also served to improve the self-esteem of the caregivers (Higgins et al., 2005). Research by Hastings and Johnson (2001) recognised that social care needs for children with ASD are extensive and this includes home-based behavioural interventions. Despite the benefits gained from social support Luther et al. (2005) identified that problems may still arise for parents seeking to join these groups, for example, with finance, as well of the timings of the meetings, which can effectively serve to exclude some parents.

The last question investigated the factors that are required for successful ICT implementation. The study established that for success factors include the provision of schools with adequate educational resources, hardware and software suitable for teaching different skills among students with ASD, and inclusion of ICT in the curriculum. Provision of financial support to obtain computers was also a significant requirement as it has the ability of solving the problem of the implementation barrier caused by the lack of finances in schools. The use of ICT to enhance communication between schools and the Ministry of Education is another important requirement, as it would ensure a real time evaluation of the whole implementation process. These findings seem to agree with Detheridge (1997), who found that training and support for teachers who teach students with ASD could enhance ICT implementation in schools.

6. Conclusion

The present report investigated the common stressors that the parents of children with autism experience and what helps them cope; it successfully identified six themes relating to the causes of chronic stress and how these are coped with. The predicted outcome and aim of the study, which was that parents of children with autism are more likely to experience chronic stress, was supported. The researcher also expected to identify that the susceptibility to chronic stress of parents of children with autism was largely due to the overwhelming guilt and responsibility felt towards their child's autism. This prediction was also supported with parent's feelings of "all-consuming" blame and responsibility.

The face-to-face qualitative interview technique was successful and yielded positive results which supported the aim of the study. However, the method does have limitations. Human error and the subjective nature of the approach have to be taken into consideration when relying on the significance of the results. This is particularly imperative when relying upon non-verbal cues such as facial expressions and eye movements as these rely entirely upon the researcher's interpretation. In order to overcome this in future the researcher could combine web-based or phone interviews. This would also allow the researcher to gain access to a wider range of participants. The present study used only nine participants, which makes the significance of the results rather limiting, although due to the nature of the qualitative analysis approach, a small number of participants is still viewed as being acceptable. A suggestion for further research would be to gather a larger sample of participants and from a wider demographic area and to combine a qualitative and a quantitative approach such as that used by Nachshen et al. (2003) in order to provide a richer data pool for analysis. Also, it would be worthwhile to compare the parents of children with autism and the parents of children with other developmental disorders to assess how the chronic stress differs and whether this is unique to autism or not.

Although six key themes were identified to contribute to chronic stress, there were some that were identified more significantly than others. A suggestion for further research would be to compare the social understandings of autism in a country where the disorder is much more prevalent, such as the United States of America or the United Kingdom, and to compare these to the results obtained from Saudi-Arabia.

The research identified that the impact of local support groups was imperative in reducing parents stress; however, as the researcher noted, the area in which the present study was conducted had only one support group. In other areas of Saudi Arabia there are virtually no support groups or links available and parents have to rely upon the Internet. Therefore, the fact that a support group was available in the area where the research was conducted cannot necessarily be considered responsible for reducing parental stress; in order to conclude this researcher would need to compare this to an area where no parental support was available.

A limitation of the present research came from the ethical issues. While working with a sample of participants from a sensitive subject, requesting the parents to discuss their child's disorder required a great deal of sensitivity from the researcher. This was particularly important in the design and delivery of the research questions. A



further limitation was that the majority of participants used in the present study were mothers. Therefore, the research cannot accurately conclude whether or not the mothers felt more chronic stress than the fathers. In future research, an equal number of father and mothers would allow for a cross-sectional analysis to be conducted to establish whether the mothers are more susceptible to chronic stress than the fathers and how this is coped with.

In conclusion, the present reports present some significant findings to understanding the coping mechanisms and causes of chronic stress in parents of children with autism. Most significantly, the lack of support, social understanding, and professional support can be largely attributed to the demographic area where the study was conducted. However, clearly the causes and implications of parental stress in autism is a broad topic with considerable implications and needs for extensive further research, particularly in countries where understanding is so limited such as in Saudi Arabia.

Reference

Alqahtani, M. (2012) Understanding autism in Saudi Arabia: A qualitative analysis of the community and cultural context. *Journal of Pediatric Neurology, 10,* 15–22. doi:10.3233/JPN-2012-0527

Al-Salehi, S, M., Al-Hifthy, E, H., & Ghaziuddin, M. (2009). Autism in Saudi Arabia: Presentation, clinical correlates and comorbidity. *Journal of transcultural psychiatry*, 46, 340-347. doi: 10.1177/13646150105823

Bailey, D.B., Golden, R.N., Roberts, J., & Ford, A. (2007) Maternal depression and developmental disability: Research critique. *Mental Retardation and Developmental Disabilities Research Reviews, Special Edition: Families of Children with Developmental Disabilities*, 13, 321-329. doi:10.1002/mrdd.20172

Barker, E.T., Hartley, S.L., Seltzer, M.M., Floyd, F., Greenberg, J.S. & Orsmond, G.I. (2011). Trajectories of emotional well-being in mothers of adults and adolescents with autism. *Developmental Psychology*, 47, 551-561. doi:10.1037/a00212

Baron-Cohen, S. (2004). The cognitive neuroscience of autism. *Journal of Neurology Neurosurgery and Psychiatry*, 75, 945-948. doi:10.1136/jnnp.2003.018713

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism & Other Developmental Disabilities*, 17, 208 – 215. doi: 10.1177/10883576020170040301

Blackledge, J. T., & Hayes, S. C. (2006). Using Acceptance and Commitment Training in the Support of Parents of Children Diagnosed with Autism. Child & Family Behavior Therapy, 28, 1-18. doi: 10.1300/J019v28n01 01

Briggs, C. (2007). Anthropology, Interviewing, and Communicability in Contemporary Society. *Current Anthropology*, 48, 551-580.

Dabrowska, A. & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of preschool children with autism and Down's syndrome. *Journal of Intellectual Disability Research*, 54, 266-280. doi: 10.1111/j.1365-2788.2010.01258.x.

Dunn, M.E., Burbine, T., Bowers, C.A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37, 39-52. doi:10.1023/A:1026592305436.

El-Sheikh, M., Buckhalt, J., & Mize, J., & Acebo, C. (2006). Marital conflict and disruption of children's sleep. Child Development, 77, 31-43. doi: 10.1111/j.1467-8624.2006.00854.x

El-Tarras, A., Awad, N., Mitwaly, N., Alsulaimani, A., & Said, M. (2012). Association between polymorphisms of SLC6A3 and DRD1 genes and autism among Saudi Arabia Taif population using PCR-restriction fragment length polymorphism (PCR- RFLP). *African Journal of Biotechnology, 11*, 11665-11670. doi:10.5897/AJB12.168

Fortunato, J. A., Sigafoos, J., & Morsillo-searls, L. (2007). A communication plan for autism and its applied behavior analysis treatment: A framing strategy. *Child & Youth Care Forum*, 36, 87-97. doi:10.1007/s10566-007-9034-2.

Fontana, A. and Frey, J.H. (2005) 'The Interview: From Neutral Stance to Political Involvement', in N.K. Denzin and Y.S. Lincoln (eds) The Sage Handbook of Qualitative Research. CA: Sage.

Gray, D.E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability*, 27, 215-222. doi:10.1080/1366825021000008639

Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3. Article 4. Retrieved June 28, 2012 from

http://www.ualberta.ca/~iiqm/backissues/3_1/html/groenewald.html

Hastings, R.P., Beck, A. & Hill, C. (2005). Positive contributions made by children with an intellectual disability in the family; Mothers' and fathers' perceptions. *Journal of Intellectual Disabilities*, 9, 155-165.doi: 10.1177/1744629505053930

Higgins, D. J., Bailey, S. R. and Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, *9*,125-137. doi: 10.1177/1362361305051403

Hoffman, C., Sweeney, D., Lopez-Wagner, M., Hodge, D., Nam, C., & Botts, B. (2008). Children with autism sleep problems and mother's stress. *Focus on autism and other developmental* disabilities, 23, 155-165. doi: 10.1177/1088357608316271.

Holloway, I., & Fullbrook, P. (2001) Revisiting qualitative inquiry: Interviewing in nursing and midwifery research. *Journal of research in nursing*, 6, 539-550. doi: 10.1177/136140960100600111

Ingersoll, B. & Hambrick, D.Z. (2011). The relationship between the broader autism phenotype, child severity and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *5*, 337-344. doi: 10.1016/j.rasd.2010.04.017

Krakowiak, P., Goodlin-Jones, B., Hertz-Picciotto, I., Croen, L., & Hansen, R. (2008). Sleep problems in children with autism spectrum disorders, developmental delays, and typical development: a population based study. *Journal of sleep research*, 17, 197-206. doi: 10.1111/j.13652869.2008.00650.x



Lounds, J., Seltzer, M.M., Greenberg J.S. & Shattuck, P. (2007). Transition and change in adolescents and young adults with autism: Longitudinal effects on maternal wellbeing. *American Journal on Mental Retardation, 112*, 401-417.doi: 10.1352/0895-8017(2007)112[401:TACIAA]2.0.CO;2

Ludlow, A., Skelly, C. & Rohleder, P. (2011) Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology*, 17, 1–10. doi: 10.1177/1359105311422955

Luther, E. H., Canham, D. L., & Cureton, V. Y. (2005). Coping and social support for parents of children with autism. *Journal of School Nursing*, 21, 40-47. doi: 10.1177/10598405050210010901.Mandell, D., & Salzer, M. (2007). Who joins support groups among parents of children with autism?. *Autism*, 11, 111-122. doi:10.1177/1362361307077506.

Nachshen, J. S. W. (2003). The family stress and coping interview for families of individuals with developmental disabilities: A lifespan perspective on family adjustment. *Journal of Intellectual Disability Research*, 47, 285-290. doi: 10.1046/j.1365-2788.2003.00490.x

Pottie, C.G. & Ingram, K.M. (2008). Daily stress, coping and well-being in parents of children with autism: A multilevel modelling approach. Journal of Family Psychology, 22, 855-864. doi: 10.1037/a0013604

Rehman, S. (2009). Autism: A generation at risk. Journal of the Islamic medical association of North America, 41, 28-37.

Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders*, 33, 383-394.doi: 10.1023/A:1025006727395

Robson, C. (2002). Real World Research: A Resource for Social Scientists and Practitioner Researchers. Oxford: Blackwell. Schieve, L.A., Blumberg, S.J., Rice, C., Visser, S.N. & Boyle C. (2007). The relationship between autism and parenting stress. Pediatrics, 119,114-121. doi: 10.1542/peds.2006-2089Q

Schopler, E., & Mesibov, G. (1994). *Behavioural issues in autism. Current issues in autism.* New York: Plenum press. Seltzer, M.M., Orsmond, G.I. and Esbensen, A.J. (2009). Siblings of individuals with autism spectrum disorder: Sibling relationships and well-being in adolescence and adulthood. *Autism,13*, 59-80.doi: 10.1177/13623613097119
Silverman, D., (2010). *Doing Qualitative Research. A Practical Handbook.* London: Sage.

Singer, G.H.S. (2006). Meta-Analysis of Comparative Studies of Depression in Mothers of Children With and Without Developmental Disabilities. *American Journal on Mental Retardation*, 111, 155-169. doi: 10.1016/S1479-3660(04)07009-X Sicile-Kira, C. (2003). *Autism Spectrum Disorders: The complete guide to understanding autism, Asperger's Syndrome pervasive developmental disorder and other ASDs.* New York: The Berkley Publishing Group.

Smith, L. E., Seltzer, M. M., Tager-Flusberg, H., Greenberg, J. S. and Carter, A. S. (2008). A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD. *Journal of Autism and Developmental Disorders*, 38, 876-889. doi: 10.1007/s10803-007-0461-6

Tehee, E., Honan, R. and Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 22, 34-42. doi:10.1111/j.1468-3148.2008.00437.x

Twoy, R., Connolly, P.M. & Novak, J.M. (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners*, 19, 251-60. doi: 10.1111/j.1745-7599.2007.00222.x

Yamada, A., Suzuki, M., Kato, M, Tanaka, S., Shindo, T., Taketani, K., ..., Furukawa, T.A. (2007). Emotional distress and its correlates among parents of children with pervasive developmental disorders. *Psychiatry and Clinical Neuroscience*, 61,651-657. doi: 10.1111/j.1440-1819.2007.01736.x

ABOUT THE AUTHORS

Lama Sahab, (Jeddah, 1988)). BSc in (Special Education majoring in Autism Spectrum Disorders, Dar- Alhekma University, Saudi Arabia), MSc Clinical Child Psychology, Anglia Ruskin University, UK. PhD in (Psychology, University of reading, UK).

Reem Balubaid, (Jeddah, 1986). BSc in (Special Education majoring in Autism Spectrum Disorders, Dar- Alhekma University, Saudi Arabia), MSc Clinical Child Psychology, Anglia Ruskin University, UK. PhD in (Education, University of reading, UK).