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'Oh No, I have an Autistic Child?!': Challenges of Mothers Regarding the Autistic Traits of their Children

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Abstract

Autism spectrum disorder (ASD) is defined as a complex developmental disorder which involves persistent challenges in social interaction, verbal/non-verbal communication, and restricted/repetitive behaviours. At present, the prevalence of ASD appears to be increasing globally, including in Malaysia. Parents of children with autism can find it difficult to cope and struggle with the demanding situations. This paper describes a case study that explores the perspectives of three mothers of ASD child. Face-to-face semi structured interviews were used to obtain their insights. Data were transcribed and analysed using the thematic analysis method. The interview revealed some challenges in relation to autistic traits which include: (i) one-way communication, (ii) alone, aloof and participate in silence, (iii) sensory issue such as super sensitive hearing, (iv) aggressive behaviour, (v) unique views, (vi) routine based, (vii) attention to details, (viii) obsessions, and (ix) moody and tantrum. The case study also unfolded that there is a need to promote the family capacity to assist mothers in raising their ASD child. Therefore, an appropriate treatment programmes in techniques for managing behavioural problems for mothers as the prime caregiver must be offered so that they are better placed to help their autistic child.

Keywords: Autism Spectrum Disorder (ASD), Autistic Traits, Mothers, Challenges, Problems.

Introduction

'Autism' derives from the Greek word of 'autos' which refers to 'self'. Schneider, Glaser and Senju (2020) stated that 'autism' is also referred to as autism spectrum disorder (ASD). ASD is described as a neuro-developmental disorder condition which is indicated by substantial impairments particularly in communication and social interaction. Many research studies

claim that these impairments are also followed by some other attributes which include repetitive and restricted behaviours, interests and activities which are demonstrated in the early years (American Psychiatric Association, 2013; Levesque, 2018; Schneider et al., 2020). Additionally, some ASD cases can be over-responsive or under-responsive to sensory stimuli (i.e., smell, touch, sound, or temperature). A research study also found that ASD occurs to approximately 1% of the population and is more common to males than females with a ratio of 4:1 (Schneider et al., 2020).

Unlike typical normal children, those with ASD require extra care and attention. Therefore, it is not surprising if parents with ASD children feel upset and pressured to look after their special child. Mothers particularly suffer from stress in coping with the heavy load of caregiving (Hartley et al., 2017). According to statistics reported by WHO (2019), 1 in 160 children globally has an ASD. This shows a dramatic increase in the number of children with ASD. A similar phenomenon is also reflected in Malaysia. The National Autism Society of Malaysia reported an increase in ASD amongst children (Kaur, Engakasa, Sivanesom & Bahar, 2015). Additionally, Dina Murad (2019) revealed that approximately 8000 to 9000 born yearly may possibly have autism. In relation to these concerns, the current research study focuses the major challenges and difficulties mainly in autistic traits experienced by mothers of autistic children. It is also hoped that services, specific programmes and supports can then be offered to these mothers and their autistic children.

Past Studies

Baxter et al (2015) reported an annual approximation of 52 million cases of autism spectrum disorder (ASD) globally which is an equivalent of 7.6 per 1000 or one in 132 persons. Guardians of children with ASD are confronted with daily challenges and various other demands in providing care for their children compared to guardians of children with other disabilities (e.g., Down syndrome) or guardians of normal children. A higher rate of stress, anxiety, depression, as well as lack of social support is reported among the guardians of children with ASD (Rutgers & Ijzendoorn 2007, Woodman et al. 2014, Baker-Ericz et al. 2016, Golfenshtein et al., 2016).

Previous studies have highlighted many factors that cause stress among parents with autistic children. One predominant factor is the children's characteristics which demand extra attention and support (Dabrowska & Pisula, 2010). Another aggravating problem is the child's lack of social skills (Pisula, 2011) which may contribute to limited understanding between the parents and child and may also affect the school and community. Behaviour problems demonstrated by the ASD children also exacerbate stress among parents (Baker et al., 2002; Ludlow et al., 2012).

Koegel et al (1992) reported a highly consistent stress levels in mothers of autistic children from different cultural spheres and geographical areas, different ages, and spectrum levels of children. More recently a quantitative study carried out by Ingersoll, Meyer, and Becker (2011) reported that mothers of children with ASD experienced greater depressed mood and higher parenting stress than mothers of children without ASD.

A child with disabilities places a weighty psychological, physical, social, and economic burden for a family (Juhásová, 2015). The parents must accommodate numerous requirements

related to their child's specific needs (Ismalina, et. al., 2016). Hence, caregiving of children with ASD is clearly demanding, resulting in great mental and physical stress for these parents.

Within the Malaysian setting, studies found that parents of children with ASD are consistently experiencing higher levels of stress compared to parents whose children are developing normally. In addition to this a clinical disorder related to psychological well-being is also detected in 53.8 per cent of Malaysian parents of children with ASD. The National Autism Society of Malaysia reported an increase in the number of children with ASD in their organisation which although reflects an increase in the awareness of ASD, also suggests more parents will have a tendency to experience high stress levels.

The existence of high stress levels among parents of ASD children is further documented in a study conducted by (Lee et al., 2017). This study compared 30 parents of ASD children and 36 parents of typical children and found that the former group of parents recorded significantly higher parenting stress levels compared to the latter group.

A quantitative study by Bakri et al (2019) was conducted to evaluate the dimensions of stress in 52 parents of children with ASD using the Parenting Stress Index 4th Edition (PSI-4) covering two domains - child domain and parent domain. It was found that the respondents scored the highest for the distractibility/hyperactivity subscale in the child domain and highest for the depression subscale in the parent domain. This shows that both child and parent domains contribute to parental stress.

Parental stress is also attributed to the lack of social skills in the ASD child. Lacking in social skills, communication problems abound which also lead to minimal comprehension between the parents and the child. In actual fact, children with ASD can exhibit behavioural issues that could build up stress on their parents. Previous studies asserted that behavioural issues seemed to be the most difficult aspect of raising an ASD child. In addition to this, it was claimed that the problematic behaviours of these children have a negative relationship to the psychological acceptance of their parents. Behaviour problems intensify the demands of parenting, which in turn amplify the stress of parenting. Additionally, the demands of parenting do not allow parents to have a lot of time for themselves which may also lead to escalating stress. Therefore, it is conceivable that the different characteristics of the children and parents are contributing to parental stress in providing care to their autistic children.

Methodology

This article espouses the case study approach which looks at mothers with autistic children on their concerns and challenges regarding their autistic child as it focuses on the perceptions of parents of children with learning disabilities. Three mothers were selected through the purposive sampling. They are Ms. N (aged 40), Ms. K (aged 43) and Ms. S (aged 46). According to Ilker Etikan, Sulaiman Abubakar Musa, Rukayya Sunusi Alkassim (2016) purposive sampling is a non-probability sampling that is useful when the researcher has limited resources, time, and workforce. It can also be used when the study does not intend to produce results that will be used to make overview of the whole population. Throughout this study, purposive sampling technique has been used by the researchers as the choices of participants are based on the participants' attribute that is mothers of an autistic child. The

main reason for choosing purposive sampling is to enable the focus on people with certain characteristics who could provide assistance to the researchers throughout the study (Creswell, 2009).

Semi-structured interview sessions were conducted with each mother face-to-face, and each session was audio-taped with an average of 90 minutes per session. The interview sessions were conducted in the Malay language. Rich and insightful data were gathered and analysed using the data reduction technique (Ismail Sheikh Ahmad, 2017), and subsequently the thematic analysis method (Creswell, 2008). The thematic analysis method enables rich data from this qualitative research by tagging individual observations and quotations with appropriate codes, to facilitate the discovery of significant themes. The audio-taped data were transcribed and to ensure the accuracy of information, they were edited. All the main points of the transcribed data were summarised and analysed, followed by further report in narrative form in the Findings and Discussion section.

Ethical considerations: At the early stage of data collection, the participants were briefed on the research project and the ethical as well as confidential issues. This is a very vital step before conducting the research (Creswell, 2012; Teddlie & Tashakkori, 2009). Using consent forms, each participant was requested to sign the form that states the voluntary nature and the aims of the study. Besides that, they were also informed that all data were solely for research and publication purposes and confidentiality would be guaranteed.

Findings and Discussion

This study sought to explore the mothers' concerns and challenges regarding the life they experienced with their autistic children. As mentioned earlier, the interview involved three mothers with the following demographic information to provide the readers with some mental images about the participants:

Ms N	40 years old
<ul style="list-style-type: none"> • Teacher at a secondary school • Married • Autistic child: Boy, aged 10, first of 2 siblings 	
Ms K	43 years old
<ul style="list-style-type: none"> • Language instructor at a public university • Married • Autistic child: Boy, aged 6, youngest of 4 siblings 	
Ms S	46 years old
<ul style="list-style-type: none"> • Supervisor at a child day care centre • Single mother • Autistic child: Girl, aged 10, youngest of 3 siblings 	

Figure 1. Demographic information of participants

From this study, our analyses show that there are several salient themes which fall under two main premises namely the challenges on the pretext of being a mother (Abdullah et al., 2022), and the other, being the autistic children themselves. This paper focuses on the latter—the

challenges faced and felt by the mothers in relation to the autistic traits of their child. The themes are illustrated in Figure 2, and they are discussed in the subsections below.

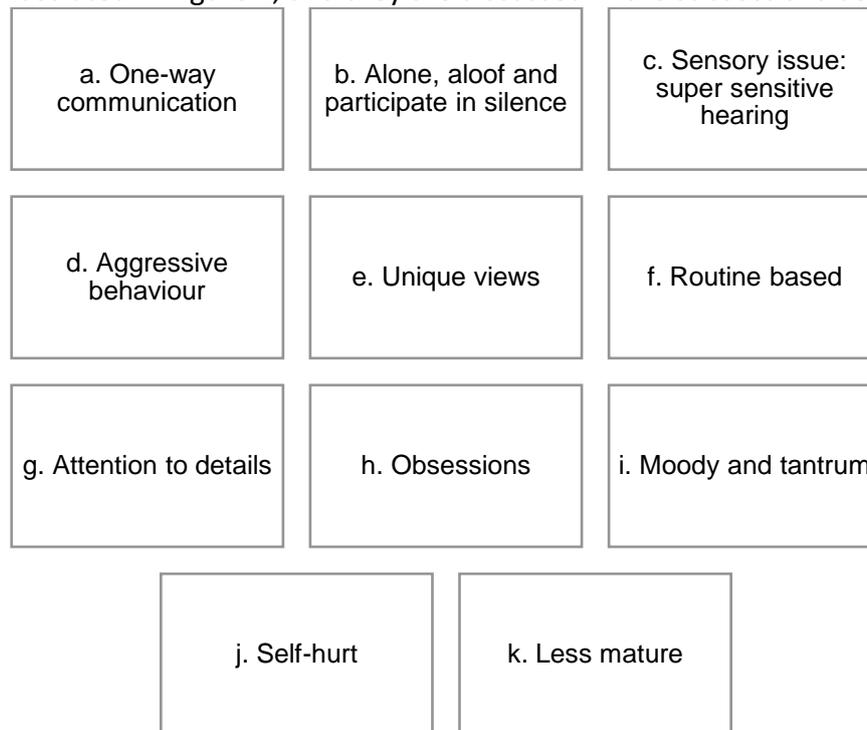


Figure 2: The traits which affect mothers of autistic children

The Traits of Autistic Children

Besides the problems faced by the mothers themselves (Abdullah et al., in press), there are also challenges which emerge from the autistic traits that are present within the child as found in other studies (e.g., Dabrowska & Pisula, 2010; Bello-Mojeed et al., 2016; Bakri et al., 2019). Acknowledging autistic traits in children is vital because of the possible educational as well as mental health implications it can have and these must be addressed for their better school adaptation (Haraguchi et al., 2019).

a. One-way Communication

Autistic children show impairments in social-communicative skills (Barbaro & Dissanayake, 2013) and they also have difficulty communicating their thoughts to other people (APA, 2013). The mothers in this study have related the same issue with their child, as illustrated in the excerpts below:

- ... It is challenging to understand the communication aspect. Two-way communication is definitely difficult (N10)
- If we ask what that or this is, he will not respond. If we ask his name, he doesn't respond. For Wafi, he responded when he was 5 (N18)
- ... If asked for something, he will just show. Doesn't want to talk. Meaning, if he wants something, he only points with his finger (N32)
- He is difficult because there is no communication, and he doesn't copy. 'I will do things my way' (N44)
- He plays on his own. No communication. We see him on the slide. But he doesn't communicate with his friends (N94)

- Another thing, her social life. She cannot make friends. Not that she can't, but she cannot get along with someone for a long period. The most is 5 minutes (S72)

b. Alone, Aloof and Participate in Silence

Following the communication and social problems that the children face, it is also difficult for them to interact (APA, 2013). They seem to be caught and trapped in their own world and are less involved in social activities both in and outside the classroom, thus having poor quality friendships, and fewer mutual friendships as reported by (Tonnsen & Hahn, 2015). This has caused the mothers to feel apprehensive as their children do not display involvement and participation. This will cause problems at the school setting where they need to react to teachers and friends in order to successfully be a part of the teaching and learning community.

- For Wafi, letting him play, he will not play with people. Even though it looks like he is playing together. But actually, he plays alone (N92)
- The issue is when people are learning, he doesn't follow instructions. He goes and sits at the back. He isolates himself (N80)
- Maybe she doesn't know how to tell. She doesn't like to share (S46)
- She likes to be alone. She likes to play under the bed (S74)

c. Sensory Issue: Super Sensitive Hearing

Another problem that all mothers in the study have declared is the sensitivity of their child's sense of hearing, as highlighted in Bolton et al. (2012). Unlike typical kids, this trait has bothered and caused headache/discomfort to them, as found in these excerpts:

- Before this I didn't know he has sensory issue. People talking too loudly (N120)
- She cannot listen to loud voices. Children crying - she cannot, it causes headache (S281)
- She sits under the table and shut her ears. She just can't (S283)
- Her hearing is very sensitive (S284)

d. Aggressive Behaviour

One more problem highlighted by the mothers is the tendency to get violent, in line with previous studies (e.g., Bolton et al., 2012; Matthews, Ly & Goldberg, 2015). Matthews, Ly & Goldberg (2015) found that one of the reasons why autistic children face peer rejection is due to aggression problems. Studies such as Moriwaki and Kamio (2013) and Skuse et al., (2009) also reveal that higher autistic traits are linked to functional impairment such as peer problems and emotional and conduct problems in school children. One mother shares her experience when her son hit his friend.

- I thought he was OK with loud noises. When he entered school, he punched his friend. The issue was because his friend talked too much (N122)

e. Unique Views

ASD children are also very opinionated, and they have their own distinctive views which can cause difficulty for parents and teachers at school to rationalise or handle them. Below are some examples of the excerpts shared by the moms in this study:

- If we ask questions, he doesn't get it. We have to repeat the question, asking it in different ways. Because his view is different from others (N139)

- For example, I told him we cannot lie and others. If I say that, huh lying, you're lying. He will say that I am wrong because I said the word 'lie' (N140)
- ... Recently they have a class presentation with marks. So, one person got 10 marks. He didn't get 10. Many got 5. So, when I asked, the one who got 10, he said the person memorised, didn't look at the paper and all. So, I told him, Wafi can get 10 too. He said he didn't want 10, he wanted 5 because majority got 5 (N210)
- The same with the communication concept. Talking to Wafi may need appropriate words. If I ask who told you, but it was not told by anyone. He read it from a book. He will not tell because nobody told him (N155)
- So, communication stops there. So, I am thinking the same thing will happen at school (N155)

f. Routine based

ASD children also adhere strongly to their routines. Knowing this will allow parents and teachers to train them to do things independently, but at times when the habitual and repetitive practices are violated, they can be painfully affected, which causes tantrums (Hood et al., 2015).

- He does the same thing. His routine. So, when there are things happening in between, he isn't aware (N187)
- At that time, it was good. So easy to train her. All the routine, daily routine is perfect. Wake up, shower ... we don't have problem asking her to do things (S5)

Extreme distress and catastrophic reactions in responses to changes in routine are rarely described in non-autistic individuals.

g. Attention to Details

In addition to the regular habit they have, ASD children are also detailed-oriented people. This is another trait that can either be good or bad, depending on how it is looked at.

- He describes in detail. For example, playing a guessing game. If we ask him to describe, he loves animals and dinosaurs. If for us, we describe the colour etc., he will describe the height, one that we don't do. We don't realise and don't know it. He takes the details (N191)

h. Obsession

A normal thing for typical kids may become an obsession for autistic children. They are found to have fanatical and fixated interests once they like something. A few examples can be seen from these excerpts:

- ... He has issues, for example to get number 1. For others, it's common because everyone wants to win. For Wafi, it affects daily things (N201)
- He's competing with his classmate. Both are autistic - equal. When it's recess time, he will finish his food because he wants to be the first to enter the class. Going out of class is another issue. He will cut queue because he wants to be the first (N202)
- When I'm driving, he will ask me to go to the right lane, because left lane is slow (N203)

i. Moody & Temperamental

Autistic children, according to their moms, are moody and have a demanding behaviour as found in some studies (e.g., Bolton et al., 2012; Mörcke et al., 2019). If things do not go their way, they will throw tantrums.

- She has mood swings (S51)
- She hits, her sister will normally be the victim (S54)

j. Self-hurt

Another negative trait that can be harmful to the ASD children themselves is that they tend to hurt themselves. Some common maladaptive behaviours in ASD children include challenging behaviours like aggression and self-injury which also affect the mental health of both the affected children and their caregivers (Bello-Mojeed et al., 2016). Below are some excerpts which illustrate the adverse effects to the children found in this study,

- She likes to hurt herself since she was a child (S63)
- For example, a pen. She will press till swollen or sore. Unless it's bleeding, she will press. Her body is full of swellings, many marks (S64)
- She doesn't feel pain. Her pain nerve is less sensitive (S67)

k. Less Mature

In comparison to other typical children, ASD kids are less mature.

- Supposedly she knows how to make friends. Maybe she looks like 10, but she still plays with 5, 6-year-old kids. When bigger it is clearer. Supposedly is matured, but still looks like a child (S90)

All these traits and symptoms have affected their personality and behaviour, which make them rather different from typical children.

Conclusion

The increasing awareness of ASD and current available knowledge has permitted us to relate to the children within this circle. In relation to this, it is essential to focus on parents, the caregivers of these children. Research has proven that parents of children with ASD has higher levels of pressure, strain and tension compared to parents of non-ASD children. Hence, there is a need of proper intervention to be given to both the ASD children as well as the family, especially the mother, the main caregiver. Their physical, mental, and psychological health need special attention too. Hence, this study to some extent has filled the gap by providing the problems and challenges encountered by mothers of autistic children, focusing on the Malaysian setting. The findings of this study may be an avenue for other mothers, especially with newly diagnosed ASD children, and make them more attentive toward autistic traits. Subsequently, this would allow them to be more prepared mentally and physically, and be more open, accepting as well as more accommodating toward their child's conditions.

The problems and challenges can be categorised under two headings – the grounds of being mothers (e.g., initial denial stage, endless sacrifices of money, time and energy, people's labelling etc.) and the ASD children themselves (e.g., tantrum, unsociable, sensory issue etc.). These have worsened the mothers' stress and increased parenting demands of their part. The findings also disclose the challenging aspects of bringing up as ASD child that subsequently support the need to promote the family capacity, especially the mothers, to assist them in raising the ASD child.

One of the suggestions is to provide suitable treatment programmes for parents especially the mothers to lessen their burden in caring for autistic children. This could be plan and carried out by relevant parties. Besides that, various stakeholders could get together and

support the ASD programmes and services for parents as well as on matters the need attention to help the future parenting policy, research, and practice of ASD in Malaysia.

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