

The challenges in raising autistic children: The voices of mothers

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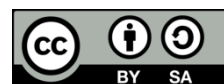
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ABSTRACT

Autism spectrum disorder (ASD) is defined as a lifetime developmental disorder usually identified by social interaction impairment, communication deficits, and repetitive behavior. The cases of children detected with ASD are rising globally, including Malaysia. Parents, as the prime caregiver to these children, face numerous challenges due to what is entailed in taking care of their children. This paper describes a case study where we examined the views and experience of three mothers, each of whom has an ASD child. Data were gathered through face-to-face semi-structured interviews, after which they were transcribed and analyzed using the thematic analysis method. The mothers narrated that the challenges they encountered include the difficulty they had in initially accepting their child's diagnosis; labelling and discrimination; phase-based temporal challenges; endless physical, emotional, and mental sacrifices; finding the strength and patience to deal with the situation; academic vs. non-academic struggles, as well as their own coping mechanisms. This paper concludes with the need to provide support for parents-especially mothers-to enable them to overcome their challenges and focus on the development of their autistic children.

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1. INTRODUCTION

Autism occurs in about 1% of the population and is more dominant in boys compared to girls, with a ratio of 4:1 [1]. Derived from the Greek word, 'autos', or 'self' in English, the term 'autism' is also commonly recognized as autism spectrum disorder (ASD) [1], a neuro-developmental disorder indicated by significant impairments in communication and social interaction, together with other traits such as repetitive and restricted behaviors that are manifested early in life [1]–[3]. It has also been found that children and adults with ASD can either be over- or under-sensitive to sensory stimuli such as touch, smell, sound, pain and discomfort, or temperature. With these existent attributes, ASD children need more attention and care compared to the 'normal' or typical children; and caring for them can be quite demanding for parents. Because of this, guardians of ASD children often face overwhelming difficulties in taking care of their children as opposed to guardians of normal children; and have recorded higher rates of tension, stress,

depression, and lack of social assistance [4]–[7]. This is even more so for mothers, who seem to shoulder the heavier burden of caring for the child [8].

For this reason, we conducted a study to explore this issue further; driven by the central research question, ‘What are the challenges faced by mothers in raising their autistic child?’ Focusing on three Malaysian mothers of ASD children, this paper highlights the challenges and problems they encountered. The insights gained from their experience could be used to help other parents overcome their own challenges and focus on the development of their own, autistic children.

2. LITERATURE REVIEW

There are around 52 million ASD cases reported worldwide, which equates to one in 132 persons [7]. It has also been found that 1 in 160 children globally has ASD [9], while in Malaysia, it is estimated that about 8,000 to 9,000 born every year may possibly be autistic [10].

Guardians of ASD children often face overwhelming difficulties and various demands in taking care of their children compared to guardians of normal children, or even children with other disabilities such as Down’s syndrome. Often, these caregivers record higher rates of tension, stress, depression, and lack of social assistance [5]–[7], [10]. A study by Koegel *et al.* [11], which looked at the stress profiles across mothers from different cultural and geographical areas, different ages, and different spectrum levels of children found that their stress levels were consistently high. A more recent study also supported the high level of stress among mothers of autistic children. In their study, Ingersoll *et al.* [12] reported that the mothers had higher parenting pressure and a higher tendency towards depression in comparison to other mothers.

One of the factors that contribute to stress among parents with autistic children is that they require extra attention and support [13]. Another problem that contributes to parenting stress is the child’s lack of social skills [14], which may contribute to a lack of understanding between the parents and child and may extend to the school and community. Behavioral problems displayed by the ASD children also add to the challenges and stress faced by parents [15], [16].

According to Juhásová [17], a disabled child represents a heavy psychological, physical, social, and economic burden for a family. This is because parenting a child with disabilities goes beyond ‘ordinary’ parenting, and the parents must cope with the many challenges associated with their child’s specific demands [18]. Hence, caring for ASD children is inevitably highly stressful for parents both physically and mentally.

In Malaysia, studies have also shown that parents of ASD children experience intensified stress levels in comparison to parents of normal children. For example, Lee [19] in their research on 30 parents of ASD children and 36 parents of typical children, discovered that the former group of parents recorded significantly higher parenting stress levels compared to the latter group. Furthermore, Bakri *et al.* [20] evaluated the dimensions of stress in 52 parents of children with ASD using the Parenting Stress Index 4th Edition (PSI-4) and 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, suggesting that both child and parent characteristics contribute to parental stress.

In summary, our review of the literature has indicated that guardians of ASD children often face overwhelming difficulties and various demands in taking care of their children. This often leads to parental stress, which can stem from the ASD child’s lack of social skills-as communication problems between the parents and the child can occur. Children with ASD may also display behavioral issues that increase the demands of parenting, which, in turn, increases the stress of parenting. Given the rise in the number of children with ASD, we saw an urgent need to conduct the study-to gain an insight into the experience of mothers of ASD children-with the aim of helping other guardians of autistic children overcome their challenges and difficulties.

3. RESEARCH METHOD

This study adopted the qualitative, case study approach in looking at the concerns and challenges that mothers with autistic children have in raising their autistic child. The goal of this study, as is the case with qualitative studies, was not to generalize, but rather, to understand, and to gain an insight into the experience and feelings of the participants [21]. To allow us to do so, three Malay Muslim mothers were selected (their names have been changed): Ms. Nia (aged 40), Ms. Khalisa (aged 43), and Ms. Sally (aged 46) through the purposive sampling method because we wanted to choose the participants that would provide us with information-rich cases-that is, individuals with specific qualities who could help us with this study [22]. Prior to conducting the interviews, we explained to the participants the aim of the research project as well as the ethical issues involved-an important step before conducting any research [23], [24]. Permission was granted from each participant through the use of consent forms, which informed them that the data were to be used solely for research purposes and that confidentiality would be assured.

Face-to-face semi-structured interviews, averaging at about 1 hour 30 minutes per session, were conducted with each of the mothers. The interview sessions were conducted in a relaxed and informal manner according to the participants' availability and convenience, and upon confirmation of the date, time, and their preferred venue. We asked the mothers to suggest a quiet place for the interview so that they would feel comfortable and relaxed. Conducting interviews in a quiet place is also important to ensure that the audiotapes were clear and relatively free of noise nuisance as this would make the transcription of the audiotaped interviews difficult and problematic. After "breaking the ice" with a few informal questions, we proceeded to ask the mothers questions based on the interview questions [22] as can be seen in Figure 1, aimed at eliciting information-rich data. During and after each interview session, we also took fieldnotes-notes of what we had observed-such as the mothers' facial expressions and body language; notes of what we felt-such as our impressions of the mothers' reactions during the interview; and notes of what we thought-such as our interpretations of their responses.

- 1) As a parent of a child with autism, what makes things difficult or challenging for you? Were there any problems you faced in teaching your son/daughter? If yes, what are they?
- 2) How did you handle them (the problems)?
- 3) Are some challenges harder to manage? Could you describe a typical challenging situation?
- 4) What makes things easier for you to handle your son/daughter?
- 5) Did you receive any support from family members or any other external sources?
- 6) What helps you cope with any challenges or difficulties you may face as a parent?
- 7) When you find any problems with them, where do you seek help?
- 8) From your point of view, what hinders the participation of your son/daughter in his/her school?

Figure 1. The interview questions

When we had completed conducting the interviews, the audio-taped data were transcribed so that they could be coded, studied in detail, and linked to our fieldnotes. The data were subsequently analyzed using the data reduction technique [25] followed by the thematic analysis method [26]. By labelling and classifying the interview transcriptions, the thematic analysis method allows rich data to be coded, which then facilitates the discovery of important themes. The main points of the transcribed data were then summarized and analyzed, and subsequently given to the participants to review to ensure that we had accurately captured and interpreted their views.

Because a central concern with any research is that the conclusions drawn are credible or trustworthy, we took the necessary steps, first of all, to ensure that the ethical considerations were followed. This involved getting the permission of the mothers to participate in the study and explaining to them the aim of the research as well as the ethical and confidential issues involved. We also took steps to enhance the credibility [21] or trustworthiness [27] of the findings by ensuring that the interview questions addressed the central research question; that the participants felt comfortable about giving their honest opinions by assuring them of the confidentiality of their responses; by confirming our fieldnotes with the audiotaped interview [28]; by carefully transcribing the interview and analyzing the data for recurring themes; and by having the participants review and verify the transcripts of their interview to ensure that their views had been accurately captured. Finally, we put aside our predispositions towards the issue being investigated and made a concerted effort to be aware of those biases that could have influenced our analysis and interpretation of the data.

4. RESULTS AND DISCUSSION

This study sought to determine and understand the mothers' concerns and challenges in raising their autistic children. Some information on the three mothers interviewed are presented here to provide the reader with a glimpse of their backgrounds. The first mother to be interviewed was Ms. Nia, a 40-year-old teacher at a secondary school; married and blessed with two sons. Her autistic son is her eldest, aged 10. Ms. Khalisa, the second mother, is attached to a public university as a language instructor. She is 43 years old, also married, with four children. Her autistic son, aged 6, is the youngest in the family. The third mother is a 46-year-old lady named Ms. Sally. She is a supervisor at a children's day-care center. She is a single mother taking care of three children. Her ASD child is her youngest daughter, aged 10. On our research question, 'What are the challenges faced by the mothers in raising their autistic child', the data yielded several recurring themes.

4.1. Difficult initial acceptance towards child's diagnosis

The most striking element that emerged from the data is that all the mothers had difficulty-initially-in accepting the fact that their particular child has ASD. It is understandable that the mothers went through a stage of being in denial as it is not easy to accept the hard truth that their children are disabled. Of course, what came next was the stigma attached to being autistic or disabled. They sensed this from their interactions with the members of their community-and worse still-from their interactions with other family members. One of the mothers, Ms. Sally, said that even her husband refused to believe that their child had ASD, hence leaving much of the 'work' to her. As she explained to us, *"Even before, the father did not help much because he also couldn't accept."*

This is a very critical juncture for parents, where they need to really understand and admit that their child needs proper care and nurturing [10]. It is at this primary stage that they-the mother and the child-will either make it or break it, because accepting the diagnosis and taking the concomitant action is critical in ensuring that they are successful in raising an autistic child.

Despite the initial difficulty in accepting the truth about their children, the mothers eventually did so, and endeavored to help their children overcome their difficulties. As Muslim mothers, they embraced the concept of *redha*, that is, accepting wholeheartedly the fact that their children are different and that this is what God had determined for them.

The mothers then moved on, searching for information on autism through associations related to ASD and educated themselves by attending classes. This helped to develop in them a more positive and optimistic attitude-that they should feel proud of the fact that God did not award these special children simply to anyone. As pointed out by Zwaigenbaum *et al.* [29], even though many families have to carry on with their tensed 'diagnostic odyssey', it is at this critical point; when mothers willingly accept the condition of their child-that they can progress to the next step, that is, to seek knowledge about ASD to provide better care for their child. Ms. Sally aptly demonstrates this when she said:

"Who wants this? Are there any moms who want a child like this? Nobody. No mom in this world would want her child to be called disabled, or defective or anything of that sort. We also don't want it. We want our children to be ok ... but thinking of it, when we go to classes, and join associations, we gradually feel proud. A bit of pride, in which God (Allah) did not award children like this to everybody."

As normal human beings, it is always a challenge to muster the courage and strength needed when facing a crisis or dilemma, especially in handling an autistic child [30]–[32]. Even though it was not easy for them, we found that the mothers had a high level of patience in dealing with the challenges in raising their ASD child. For instance, one mother relied on her maternal instincts when she felt that something was not right. Situations such as recognizing delays in their children's development and dealing with their unpredictable tantrums require that the mothers brave the difficult situations. The mothers related to us that they had 'metamorphosized' into more patient individuals.

4.2. Labelling and discrimination

The mothers also had to deal with the perceptions of society and that of their children's peers. This was also described by previous researchers [33], [34] as being the experience of many parents of children with ASD, which has often led to labelling and discrimination [35]. It was a painful experience for the mothers when their other children were stigmatized for being the brother or sister to a 'disabled'. Putting up with the stigma was difficult for both the mothers and their children, but children are more affected when labelling leads to discrimination. Ms. Sally's daughter, for example, refused to look after her little sister with ASD as she was embarrassed by the behavior and appearance of her disabled sibling. Ms. Sally's daughter (the elder sister to the autistic child) said:

"I don't want (to take care of her at school). My friends will say that I have a disabled little sister. They always make fun of me because of that."

Ms. Nia relates how labelling can be a serious issue in handling ASD cases. Her son once hit a friend because he could not stand the noise that his friend was making. If he were to be labelled as a child who hits other children, this would not be fair as they do not really know the real reason behind it. Ms. Nia went on to elaborate:

"If Ali punched someone, Ali is wrong."

She agreed that Ali should not have done that, but she wanted people to ask what could have caused him to do that.

“Why all of a sudden he goes around punching people.... Because if he wants to explain, I don’t think he can. He cannot tell why. In the speech phase itself, we have to teach him how to answer ‘Why’ questions. The ‘Why’ must be taught.”

Ms. Nia was concerned that autistic children such as her son would be labelled without knowing that there were reasons behind their actions, such as their inability to tolerate noise, which is reported to be one of the characteristics of autistic children due to the nature of their sensory processing [36].

Whatever efforts the mothers undertook to protect their children from embarrassment, there was still the labelling and discrimination by their friends-especially when both the normal sibling and the ASD child are in the same school. The mothers also felt that due to discrimination, many parents choose not to declare that they have a special child for fear of the negative remarks that may be thrown at them. The culture of labelling has made these mothers become hesitant to open up, as blurted out by Ms. Nia:

“Labelling - once we put a child under special needs there will straightaway be a certain mindset. Sometimes parents refuse to declare. On Facebook people will say many things making them uncertain whether to open up or not. This is because of labelling.”

Hence, there is a need to address the issue because ASD children are not like other children. People need to be educated on and made aware of the needs and nature of autistic children, who are increasingly present in the society [10], [37]. These worried mothers are hoping that there be some kind of assistance that would help their children to adapt-and not to be discriminated against for certain expressed behaviors that are often beyond their control. They are concerned that the children, once they become adults, are not recognized by society as those with special needs [38], and even if they are, they may not be aware of how to handle them due to lack of knowledge and understanding. This is echoed in Ms. Nia’s words:

“There must be some kind of assistance in terms of helping the ASD children; because I think after Form 5, they will be 19, and they will live like other people. So, they will be our neighbors. If they do awkward things, it means that we have isolated them—we have not prepared them to live among the “normal” members of society.”

Not only are the ASD children not made ready to live amongst the members of society, but also the people are also not trained to be alert or mindful about the ASD children. This can cause people to make wild assumptions, as explained by Ms. Khalisa:

“But we didn’t prepare the society to recognize who are the ones with special needs. One more thing, what to do with them? We will assume many things if we don’t know or don’t understand.”

4.3. In search of suitable schools and expert centers

Another major problem that the mothers faced is the struggle to locate suitable schools for their ASD child. Finding the right school is of primary importance because better social outcomes could be achieved if the children are given the chance to mingle and socialize with their normal peers [39], [40] as this would help them to develop better self-esteem and self-concept [41], [42]. All the mothers admitted that often, they get rejected by kindergartens since their children display unruly or peculiar or challenging behavior. Ms. Nia’s words represent the voices of the other mothers, who shared a similar experience:

“At 5 years old, I sent him to a kindy, and was rejected, because he didn’t sit, refused to follow instructions ... After that, I sent him to the second kindy....”

Like many other mothers [35], [43], [44], the mothers in this study also had difficulty looking for credible centers that offer expert services such as speech and occupational therapy, which are rather limited in Malaysia. They believe that experts play a crucial role in helping and managing ASD children, and that every school should have at least one of these experts. As affirmed by Ms. Sally, *“Services like these are not many.”*

4.4. Phase based temporal challenges

When asked about one of the greatest problems or challenges that they had faced, the mothers pointed out that these varied according to the phases in their children's development. Every phase would present a unique predicament, from early childhood to high school. As expressed by Ms. Nia:

"I think every phase presents a different challenge. I mean, during childhood, I wanted him to have two-way communication. Once two-way communication was achieved, there was the school issue. Ok with the school issue, we looked at his classmates ... never ending."

One of the challenges that they faced is the different approaches that they had to use in teaching and handling their children-to cater to their children's level of development. The mothers tried their best to learn about and adapt themselves to these new approaches, although they may have started to feel comfortable with an approach that was deemed suitable for their children at the time. Ms. Nia, for example, expressed the fact that she put in a lot of effort when her son was a toddler, i.e., during the initial phase when he was diagnosed with ASD, and also when she had to prepare him for kindergarten.

"The most effort that I put in was when he was 4 or 5 years old... when he had just been diagnosed with ASD-and when he entered school. That was the most-because we wanted to help him with readiness for school."

Ms. Sally shared the same point about having different priorities at different phases of her child's development. During the interview, she told us that because her daughter was about to be 10 years old, she was focusing on helping her with the academic aspect-especially reading-because she thinks that reading is a skill for survival in this world. Ms. Khalisa, whose son was 6 years old at the time of the interview, and entering Year 1 of primary school, also said that literacy was her focus at that point in time, compared to when her son was younger, when she focused on his ability to speak, as evident in the excerpt:

"... right now, I would like to teach her the academic aspect ... she still cannot recognize ABC."

Like most other mothers, the mothers in this study were also concerned about their child's education. However, having an autistic child had forced them to view the academic route aspect of their child's development rather unconventionally. During the early stage of diagnosis, most of the mothers did not place high expectations on their child's academic abilities, but channeled their concerns towards their social traits, as research has found that autistic children have social complexities [20]. Because of this, the mothers placed more stress on building their child's social skills as they had observed that their children could not get along with their peers-they were not able to communicate and ended up playing alone.

However, when their child became older-for example, when they were in the upper primary-the mothers started to feel apprehensive about his or her academic ability as they regarded this as being a key factor in the well-being of their child. As mentioned by Ms. Sally, whose daughter is good at memorizing, she still could not read at the age of 10. Although studies have reported the fact that ASD children have special abilities, the mothers still believe that their child needs to fulfil the academic aspect and that ASD children need more assistance when it comes to the academic setting [45]. In fact, Ms. Khalisa mentioned that it is unthinkable to her if her son goes through life not knowing how to read.

4.5. Endless physical, emotional, and financial sacrifices

The mothers related to us how they have had to endure endless hardships and how they had to make numerous sacrifices for the sake of their children, as was also reported by previous researchers [5], [46]. Ms. Nia mentioned the laborious journey to the government hospital from her house when sending her son for therapy sessions. After some time, due to her inability to continue because of the distance as well as lack of time and energy, she resorted to the services of a private therapy center which was closer to her home. But this was at the expense of her finances, as the center was costly.

"It is hard to commute to HUKM, an hour from home ... so we took the private occupational therapist which is closer to our house, even though it's a bit expensive."

Another mother, Ms. Sally, also had spent RM 300 to RM 400 (around USD 72–USD 97) per session for her child's assessment and had invested thousands of Malaysian Ringgit (USD 1=MYR 4.14) on therapists. Meanwhile, Ms. Khalisa was also concerned about the importance of having more experts. According to her, parents would be willing to spend a certain amount of money, if they have to, but the availability of experts is scarce in Malaysia, a situation that is also reported by Murad [10] and Toran [43].

“There must be. If there are, even though with charges ... parents want the service. But for now, like me, I want it. But it is hard to find the right therapist.”

In addition, Ms. Nia reported having to sacrifice her own career advancement when she decided to take unpaid leave to concentrate on taking care of her autistic child. *“I took unpaid leave for 3 years and 7 months”* which is indeed a huge sacrifice on her part as this affected her career progression—but a sacrifice she was willing and all ready to make.

Reflecting on their experience, the mothers said that they also needed to be adaptable, which can cause them to be mentally and emotionally drained. There is no “one size fits all” when it comes to addressing problems related to their children, they said. For example, they needed to figure out which method best suits their child when problems occur, as mentioned by Ms. Sally:

“Sometimes the problem is similar, but the way to handle it is different. It depends on individuals. It may be that my child is an autistic child too. But when doing the same thing with my child, it is not the same ... so we must be adaptable and flexible to adapt things for our child.”

4.6. How the mothers coped

Raising and educating their ASD children has not been an easy journey for the mothers. There were many challenges and difficulties, there were many problems that needed to be overcome, there were ups and downs, and there were even crises that they had to endure. But through it all, the mothers found the strength to cope. Like other parents, as has been described by previous studies [31], [44], the mothers found strength in putting their faith and trust in God, the One and Only. One of the mothers, Ms. Sally, found herself earnestly asking for God’s help in solving the situations pertaining to her child, and accepted the fact that indeed, God’s plan is the best. By submitting to Him, it made her stronger—non-dependent—except to God the Almighty. She also allowed tears to flow more readily, as crying is an excellent way of releasing emotions and processing difficult situations. With that, she could regain her strength and readily face whatever is to come. This can be seen through Ms. Sally’s exact words:

“Firstly, we have to calm ourselves down. We need to be patient, to ‘istighfar’ to get the strength from Allah to show us the right way. To remind ourselves that Allah sent her to us. Not solely for us, for us and for people around us. People might view this as easy. But to make ourselves patient is a problem too. So, I think this is a way that Allah wants to draw me closer to Him. I feel this is the silver lining, because I think now, I am stronger than before.”

The mothers also built their strength through the support they received from their husbands, as shared by Ms. Sally:

“... I would always call my husband.”

The experience they went through is congruent with that of other studies [47], [48] which state that in reality, autism does not only affect the mother; but also, father. They also obtained assistance from other extended family members such as the father-in-law in terms of the financial aspect, and siblings in terms of understanding and care.

The mothers also kept seeking for knowledge and relevant information on autism to help them manage their ASD children better. They would normally read relevant materials and books and attend talks as mentioned by Ms. Sally and Ms. Nia.

“Find knowledge, find information. Find all the related books, to get to know the traits and all. Some people say we have to treat them like normal so that they feel normal. But there are certain things that we cannot treat them like normal.”

In addition, the mothers would also join support groups through social media or other sources to help them cope with the challenges they faced. Befriending other mothers who are in the same boat also helped them to weather the storm in raising their ASD child. They also admitted that many opinions were given when it came to advice on how to deal with their child. However, they would selectively choose the information and adapt them to suit their own child’s needs.

5. CONCLUSION

Much of the current research on ASD has focused on children or students with ASD, hence creating increasing awareness of their plight as young members of society or as students in inclusive classrooms. At the same time, it is also necessary to focus on the parents, who are the caregivers of these children. As previously mentioned, research has shown that parents of ASD children face higher levels of pressure, strain, and tension when compared to parents of non-ASD children. The findings also point to the need to focus not only on the ASD children themselves but also on the non-ASD siblings and family members as they also suffer in various ways not only from the interaction with an ASD sibling, but perhaps also from the lack of attention by the harried mother. All these aspects need to be given due attention when addressing the challenges in raising ASD children. However, this paper focuses specifically on the mothers, who are usually the primary caregivers of their child because the physical, mental and psychological health of the mothers demand special attention as they often bear the brunt of the responsibility for raising their children.

In this paper we share the stories of Malaysian mothers of children with ASD, specifically, the challenging aspects of raising an ASD child. It is hoped that their stories would be able to provide the reader with an insight into the experience of mothers taking care of their autistic children—stories that other mothers can relate to; from which they would also know that they are not alone. It is also hoped that the stories would provide mothers with the needed support and encouragement in raising and making choices regarding their ASD children. The problems and challenges that these mothers have encountered have increased their parenting demands and have exacerbated their stress. It is suggested that the appropriate programs be planned and carried out by relevant parties for parents (especially the mothers) to reduce their burden of caring for their autistic children.

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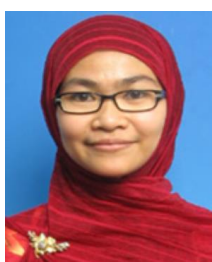
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