

## **Mother! I'm Autistic. Am I a Burden to You?**

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### **Abstract**

Having children with Autism Spectrum Disorder (ASD) is a demanding undertaking, which requires high commitments from their caretakers. In response to this, this research was conducted to explore the lived experiences of low-income mothers with ASD children. This research is qualitative research, which utilized the Interpretative Phenomenological Analysis (IPA). Four participants were recruited for the present study, consisting of low-income mothers who have children with ASD and a monthly household income of less than MYR3000. All participants completed at least two semi-structured interviews and were recorded digitally, transcribed, analysed, and interpreted. The analysis showed that the participants perceived having ASD children as a challenge. They associated the challenges with mental preparation issues, difficulties in the career adjustments process, conflicts in child care, and the differences in parenting approaches. As an implication, understanding mothers' experiences with ASD children is crucial towards providing the necessary supports.

**Keywords:** Autism Spectrum Disorder, Low income, Mother, Children, Malaysia

### **Introduction**

Autism Spectrum Disorder (ASD) refers to a developmental disorder with symptoms that include persistent deficits in social interaction and communication (Diagnostic and Statistical Manual of Mental Disorders DSM-V, 2013). ASD children mostly display restricted and repetitive behaviour as a mechanism to self-soothe (Kanner, 1943). They frequently flap their hands, rock back and forth, and even banging their heads on the floor (Aiman, 2019). They also experience difficulties in engaging and having interactive conversations with other people. Some also have a limited heart-to-heart interaction with their parents, which causes some problems in controlling their behaviour. This challenging situation hindered progressive parent-child relationships, and parents feel overwhelmed with child-rearing responsibilities (Kanner, 1943).

While the challenging situation continued for parents, ASD children would face a difficult life course to live independently. ASD children present numerous challenges towards their

caregivers (Johnson, Butter & Scahill, 2019). Thus, systematic intervention and effective support systems are necessary to safeguard the survivability and sustainability of parents and their ASD children. Moreover, raising a child with ASD can be exhausting, burdensome, and more expensive than caring for children with other disabilities (Hayes & Watson, 2013). Hence, low-income families need to be addressed as they face potential challenges that differ from higher-income groups.

In the Malaysian context, approximately 300,000 individuals are diagnosed with Autism spectrum. However, only 20,000 (0.067%) of them sign on for the Persons With Disabilities (PWD) cards (Radhi, 2018). This low percentage of registration shows parents' reluctance to register their children, maybe due to denial, whereby refusing to accept the abnormality of their children, which leads to making wrong decisions on their child's treatment plan (Autism Speaks, 2018).

In Malaysia, citizens are categorised into three income groups, which are Top 20% (T20), Middle 40% (M40), and Bottom 40% (B40) (Department of Statistics Malaysia, 2016). T20 and M40 household income consist of MYR13,148 and MYR6275, respectively, while B40 earns a monthly household income up to MYR3000 (Department of Statistics Malaysia, 2016). The implications of having an ASD child in a B40 household include potential financial constraints. With limited public treatment services available and expensive private care, these parents faced difficulties in maintaining a healthy family life cycle and quality of life (Shin Ying, Mohd Normal, McConnell, Tan & Singh, 2018). Both M40 and B40 households continue to struggle financially in making a decent lifestyle even in a 'normal' home. Having a child diagnosed with ASD raises potential challenges and difficulties in household operations (Harinthavimal, 2019).

In the present research, the focus is on mothers of ASD children. It is vital to address that healthy maternal attachment plays a crucial role in children's mental well-being (Bowlby, 1951). However, mothers' experience in developing the relationship process to ensure their child's individual needs being met has yet to be discovered systematically and scientifically. Hence, this research sought to understand the life experiences of low-income mothers with ASD children and the coping strategies used to overcome them. This exploration will help understand the challenges faced by low-income mothers with ASD children in today's competitive economic environment. This research aims to fill in the literature gaps, develop new knowledge, and propose strategies to support ASD children and their families. The key research questions were the life experiences of low-income mothers with ASD children and the coping methods. In answering the research questions, a qualitative study was completed, which interpreted these mothers' in-depth experiences. The present research reported on the mental preparation and the adjustments of career and parenting methods were amongst the challenges faced by them.

## **Methods**

### **Research Design**

This research was conducted using a qualitative approach, utilizing the Interpretative Phenomenological Analysis (IPA) which seeks to understand the way people make sense of their life experiences (Cropley, 2002; Smith, Flowers & Larkin, 2009). This research attempted to investigate and interpret the 'lived experiences' of participants who share a common phenomenon (Alase, 2017) to gain a more profound understanding of not just the observable experiences but also the subjective psychological experience of the participants. These include feelings and how their own unique experiences meant to them.

In conducting IPA, it is essential to consider the three critical areas of the philosophy of knowledge that underpin its development i.e. phenomenology, hermeneutics, and idiography. Phenomenology was developed by Edmund Husserl, which focused on how individuals view their experiences (Pietkiewicz & Smith, 2012). In conducting this research, significant individual experiences were identified, which made them distinguishable or unique compared to others (Pietkiewicz & Smith, 2012). The second philosophy is hermeneutics, which refers to the interpretative property (Smith et al., 2009) that the researcher uses to understand the participants' view by putting oneself in their shoes while interpreting and making sense of that experience (Pietkiewicz & Smith, 2012). Double hermeneutics is often used in the analysis process, which refers to "the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world" (Smith, 2004, p. 40). Therefore, the interpretations are bounded by both the researcher's ability to dissect those experiences and the participants' capacity to articulate them (Noon, 2018). In the present research, hermeneutics was practised by exploring the participants' meaning-making process of their experiences with autistic children. The third philosophy is idiography, which is "concern with the particular" (Smith et al., 2009, p. 29). It emphasizes the in-depth and detailed examinations regarding the participants' unique context of making sense of the current event; it seeks to understand each person's individual story by using in-depth, individualized analysis for a deeper understanding of the participants' trait of thoughts, beliefs, and behaviours (Noon, 2018). In line with this principle, in this research, idiography was emphasized by conducting a detailed analysis case by case and treating them differently.

### Participants

Four participants (N=4) who participated in this research were recruited from Autism centres and associations in Selangor, Malaysia. These participants were carefully selected through purposive sampling based on several inclusion criteria consistent with the objectives of the study, namely, i) a mother, ii) having at least one child diagnosed with Autism Spectrum Disorder, iii) with a monthly household income MYR3000 or less (B40 criteria), iv) lives in an urban area, and v) willing to participate. Pseudonym names were used to replace original names. The profiles of the participants have been summarised in Table 1.

Table 1

#### *Profiles of Research Participants*

No	Name	Age	Household Income (MYR)	Employment	No of ASD Children
1	Siti	35	2500	Self-employed-Tailoring	2
2	Nurul	38	3000	Housewife	1
3	Hawa	38	3000	Housewife	1
4	Yana	45	3000	Housewife	1

### Research Procedures

A local autism centre was contacted for approval in recruiting participants. After the permission was given, potential participants were proposed by the centre based on the pre-determined inclusion criteria. The researcher then met the proposed potential participants and explained the research process, the purpose of the interview, confidentiality, interview

procedures, and their rights as a participant. An agreement was made that the participants were voluntary. The participants had the right to withdraw at any time. The contact information of the researchers was given to all participants. Once the participant agreed to participate in this research, they had to read and sign the informed consent sheets. The time and venue of the interview were then arranged.

The interviews were conducted in a closed and private classroom with minimal distractions to maintain the participants' privacy and confidentiality of information. The audio recording was used throughout the interview session with consent from the participants. Sound recording and note-taking are essential in ensuring every piece of data can be transcribed and analysed further. The duration of each interview session ranged from 40 to 50 minutes per session. All interviews were conducted in the Malay language to maintain the comfortable mood of the participants. The conversation mode was semi-structured, whereby a set of questions were prepared to assist the researcher in meeting research objectives (Lopez & Whitehead, 2013). An interview schedule was used as a guide, and there was no particular order in asking the questions. The interview consists mainly of open-ended questions, and the question revolving around the 'why' and 'how' was often used (Adams, 2015). Questions like "how is your life having an Autistic child" and "how did you feel knowing your child has Autism?" were asked. The questions were very general, whereby the participants were free to answer in any form they like. Some of the participants were very responsive, but some did not manage to give an in-depth answer. Hence, probing questions were used to draw out more information and uncover deeper meanings in the topic of interest (Ryan, Coughlan & Cronin, 2009).

### Analysis

All transcripts were analysed using the IPA. The seven analysis steps proposed by Smith et al. (2019) were adopted and adapted to the present research. These steps were 1) reading and re-reading, 2) initial noting, 3) developing emergent themes, 4) searching for connections across emergent themes, 5) moving to the next case, 6) looking for patterns across situations, and 7) taking the interpretations to a deeper level. These analytic processes were multi-directional, which means room for flexibility and a constant shift between the methods (Smith et al., 2009).

Table 2

#### *Sample of Initial Coding Process*

Line	Transcripts	Interpretation/Noting	Emerging Themes
42-48	<i>Haa when my son had to enter this centre, I cried because I have difficulties trusting other people to take care of my child. That is the problem. Since the beginning, when I had to work and sent my child to the babysitter, also I have problems with that, and the babysitter also didn't do a good job. So when that happened it made me felt traumatized, afterwards when I had to send my son here in the centre, I kept thinking how he</i>	She has difficulty allowing others to take care of her kids.  She has experience sending her children to a problematic babysitter.	Difficulty trusting others to take care of the child (Trust issues)

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	<i>is going to survive with so many kids. It made me very very worried.</i>		
<b>115-118</b>	<i>One is because no choice, but after that because okay I guess it's a blessing also that my child has already been here for three years. Three years with Teacher Sheela. Teacher Sheela is very good. Really she is very very good and she knows what my child wants. So we feel relieved</i>	How does she cope having to send her kids to IDEAS? She thinks that she has no choice and thanks to a good teacher that help to take care of her children.	Need a trusted and good teacher that understands her child
<b>126-129</b>	<i>In the beginning, I had a job in a company. After 10 months, it was before the diagnosis that my son was constantly sick and had to go in and out of the hospital, so I just can't handle. During the 10 months of work I was given 2 warning letters and at last resign. So I opened my own business and worked on my own.</i>	Lifestyle changes. She had to resign to take care of her children.	Career changes to suit her time taking care of her child

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The researchers started by reading and re-reading each transcript to be familiarised with the data. Then, listening to each audio recording while reading the transcripts helped to understand not just what the participants had verbally said but also the feelings and emotions tied to them. This process involves the researchers to immerse in the original data (Smith et al., 2009). Afterwards, the researchers carried on by writing notes regarding any observations and reflections on the experiences or comments of potential significance on the transcript's margin (Pietkiewicz & Smith, 2012). Upon completion of step two, an understanding of the participant's experiences was developed, which led to conducting in-depth follow-up interviews.

Then, the researchers moved on to step three, which was developing emergent themes. Significant statements were extracted with the notes and interpretation as well as the possible emergent themes. At this stage, the analysis was still conducted case by case before merging between instances. Table 2 shows the initial analysis process of generating emerging themes.

After generating emerging themes from each case, the researchers moved on to step four, searching for connections across emerging ideas. Within each case, any links or patterns within the themes were identified, and merge the items that fit together (Smith et al., 2009). It is also important to note that the whole analytic process of steps one to four was conducted on a single transcript. After the completion of stage one to four in the first case, the researcher continued with step five, moving to the next case. The whole process of phase one to four was repeated with the following circumstances until all evidence had been analysed.

After generating and clustering all the themes case by case, the researchers continued with step six, looking for patterns across cases. It began by merging all relevant themes between all participants. After refining and finalizing the ideas, a table of the subject was formed, consisting of superordinate and subordinate opinions (Smith et al., 2009). The completion of the table of themes had a sense of satisfaction. We managed to capture all the significant issues about the participants' experiences and interpretations. Several methods were used to verify the final themes. Inter-rater reliability was adapted whereby the data collected were

independently analysed by the researchers and determining the level of agreement between them (Armstrong, Gosling, Weinman & Marteau, 1997). The researchers interpreted the participants' data individually, and frequent discussions were conducted among them to locate the participants' unique experiences (Heale & Twycross, 2015). The falsification method was also used to validate the emerging themes by formulating new statements to falsify the hypothesis (Dirk, 2007). In the present research, alternative topics were generated to replace and forge the researchers' initial ideas.

## **Results**

The analysis showed that upon having ASD children, these mothers' life experiences went through significant change. The changes that happened were to please their child's condition and needs. Specifically, the themes that emerged from the transcripts revolve around the changes in their role as caregivers and adjustments in daily routines. The participants were concerned about the condition of their children and ways to ensure their needs being met. They highlighted mental preparation issues, trust issues in child care, career adjustments, and changes in parenting approaches. Through these themes, the participants expressed concern towards their own lives to ensure they provide the best for their child with ASD.

### **Mental Preparation**

Most of the participants reported that their children received the diagnosis as early as two years old. Hearing the news about the result of the diagnosis was a daunting experience. Without necessary preparation, the experiences' impact would be disruptive in many aspects, especially the mother's psychological well-being. Therefore, the participants asserted the importance of physical and mental preparation as the mother's keys to adapt to raising children with autism. Mental preparation in the present research refers to the mother's psychological readiness to have a child with developmental disabilities. The participants were generally expecting a typical child, and the diagnosis's news was out of their expectations. Having a child with special needs and developmental disabilities is demanding and unexpected to parents, often which they are unprepared for (Dervishalaj, 2013). Also, autism was very new to them. They had limited knowledge about autism and had no experience dealing with special needs children. They did not know what to do and felt down, knowing that their child will not be the same as others.

"I felt very blur you know that blur feeling like my mind is empty and didn't know what to say so I just kept quiet. Because of that. 'Mmm' to say that I couldn't accept the diagnosis yes I couldn't accept it until I cried." (Hawa, 20)

"'Hmm' at first I was sad like I couldn't accept it right. He (my son) looked okay when he was young. But some time until now I'm okay. After three, four years okay." (Yana, 28)

This disappointment would not emerge if the participants were mentally prepared and equipped with sufficient knowledge. Mothers who had learned about giving birth to a premature child will take the initiative to learn more about the disorders and their consequences to their children. They felt responsible for equipping themselves with proper knowledge and skills. Hence, after their child being diagnosed, they were mentally prepared and able to accept the news.

"'Umm' so when he was around 2 years old, the doctor confirmed his diagnosis with autism. So far I'm okay I didn't feel down. It's not like he needs to go in and out of the

hospital or need any operation. So just be positive it's okay doctor said let's just conduct therapies." (Siti, 18)

"Before Alia was diagnosed and before she went for EIP I have asked around and search in Google about these kind of things. So I have that already, me and my husband already standby in case anything" (Nurul, 182)

Thus, based on these accounts, the mothers' feelings were well adjusted when mentally prepared. They gained support from doctors, friends, and family. They educated themselves with the right knowledge on measures needed to be taken for their child's well-being.

### **Trust Issues**

As individual children's needs are different (Jaarsma & Welin, 2012), children with ASD tend to display behavioural deficits, overwhelming for parents (DePape & Lindsay, 2014). Hence, they need special attention and education right from birth (Tongerloo, Wijngaarden, Gaad & Lagro-Janssen, 2015). The daily care for ASD children requires substantial repetitive tasks such as personal care, teaching, and training life skills (Tongerloo et al., 2015). With such an overwhelming time needed to care for their child, it was difficult to find people who could be trusted in taking care of their child. They faced difficulties looking for well-trained child care to provide proper care for their child (Sitimin, Fikry, Ismail & Hussien, 2017). One of the participants, Siti, expressed her anxiety when sending her son to an Autism centre. The previous lousy experience left her with these trust issues towards other people.

"Haa' when my son had to enter this centre I cried because I have difficulties trusting other people to take care of my child. That is the problem" (Siti, 42)

Siti also thought beyond her child's needs of a primary caregiver. She was concerned if a sudden absence of her or her husband as primary caregivers happened to her son. Thus, she was worried about her son not being able to survive independently without her husband's presence.

"Actually the challenges that worried me the most is that in case if anything happened to me and my husband, my children can't stay with anyone else. That is the biggest problem for me towards my children" (Siti, 358)

Another participant, Nurul, chose to take care of her children by herself because she could not rely on the child care centres to take care of her child's basic needs. She shared how most of the kindergarten does not provide special education for children with ASD.

"Majority of my friends that sent their ASD children to Taska (Kindergarten) have problems and their children refuse to eat, because they don't know how to communicate. They don't know how to inform whether are they hungry or not and other people are not aware about this therefore these children will be neglected. So it's better that I take care of my child myself" (Nurul, 193)

Thus, due to the lack of professional day care centres to provide proper care for ASD children, the mothers continue to receive lack of support in caring for their child.

### **Career Adjustments**

Most participants were employed. However, upon having their ASD child, they had to make career adjustments to ensure their child's needs were met. ASD children have poor basic life skills and need special care and assistance from their caregiver. These adjustments caused the mothers to re-evaluate their career goals and consider the condition of their child (Shin Ying et al., 2018). Before having an ASD child, Nurul had a job and was able to earn some additional income for her family. However, after knowing her daughter's condition that needs

constant care and supervision, she quit her job to be a full-time housewife and caregiver. She knew that she was the only reliance person on her child. Being a housewife enabled her to spend more time supervising and ensuring her child received the necessary healthcare.

“But before Alia was born, I did work for a while as a teacher at my other child’s Kindergarten. And then once Alia was born, I couldn’t continue. Not because of Alia that I quit my job but because of Alia’s condition, I know I can’t continue working” (Nurul, 229)

On the other hand, although balancing work and family life was difficult, Siti did not give up her career but looked for alternative work opportunities. Initially, she worked for a company and struggled to attend to both work commitments and her sons’ needs. Giving up on her career was not an option, but being a full-time housewife instead. She decided to venture into a start-up business, which gave her more time and flexibility for her children's care.

“In the beginning, I had a job in a company. During the 10 months of work I was given 2 warning letters and at last resign. So I opened my own business and worked on my own.” (Siti, 126)

This finding complements a study by Shin Ying et al. (2018), whereby having an ASD imposes a significant impact on mothers' lives. They had to re-evaluate their career goals to consider their child's specific needs in the middle of work and family commitments. Siti chose to prioritize her children while being flexible and have a career on her own.

### **Changes in Parenting Approaches**

The roles of a mother are discussed in this section. The participants highlighted the strategies they adopted in taking care of and educating their ASD children. It is important to note that the participants' parenting approaches differ from one to another, depending on their knowledge and experience (Bornstein, Cote, Haynes, Hahn & Park, 2010). Also, the approaches reflect the cultures and values upheld by each participant and their expectations towards their children (Bornstein et al., 2010). In this vein, the participants underlined their adjusted roles as a mother.

#### *High Involvement in Child’s life skills training*

Due to their concern on the inability to live independently among ASD children, the participants need to manage effectively to provide appropriate support for their ASD children. However, the formal education systems least likely provide a platform for ASD children to learn about religion. As such, Siti tried her best to teach her son informally at home. She believed that it is her role as a parent to ensure her son understands religion.

“Basically I want my son to understand basic knowledge about Islam. So at home I will teach him like now I’m teaching him how to read the Al-Quran ‘lah’. In school they don’t teach these things so I’m trying to learn as well how to teach my son” (Siti, 156)

Meanwhile, both Yana and Hawa put in the effort to ensure their child lived independently. They taught them necessary daily life skills and how to behave according to the norms of society.

“The simple things like eating, bathing and brushing his teeth. Those daily routines ‘lah’ like that. If he is eating, then he needs to sit properly right so I’ll tell him. The simple things if difficult then he won’t understand right” (Yana, 162)

“And then teach him the things like normal people do such as cleaning and doing house chores. I will teach him things like these bit by bit (Hawa, 98)



Regarding formal education, Siti emphasized the importance of being involved in her son's activities in school. Family education involvement and parent-teacher relations, are crucial in providing a supportive environment for children with ASD (Garbaz, McIntyre & Santiago, 2016). The involvement in the activities has developed their empathy and increased their support for their children.

"Have to take part 'lah' if not how are you (as a parent) going to know how the teachers handle ASD children. And then you (other parents) don't even want to be involved with your own child's activities. For me I like to be involve and I felt pity towards the teachers having to take care of all the children (Siti, 202)

#### *Employing creative parenting in behaviour control*

ASD children have limited mental capabilities to understand and face difficulty in communicating and interacting with other people (Diagnostic and Statistical Manual of Mental Disorders DSM-V, 2013). Therefore, approaches in dealing with the child's behaviours vary as shared by the participants. They suggested special techniques that were necessary to train the children. They proposed using specific supportive and pleasurable tools to handle their child's behaviour. As such, Siti explained how using mobile phones can distract her son is behaving when other people were around. These techniques could be used in public venues such as restaurants, hospitals, and visitors in their own homes.

"Sometimes (I give phone to my child). Usually when we are at restaurants because we can't handle right. We also want to have our meal. Then I will give (Siti, 251)

One way to condition ASD children and promote positive behaviours is by providing pleasurable tools to them as a reward. Yana explained how she also used mobile phones as a reward for her son after completing specific tasks. This mobile phone usage is a motivation for her son to complete more jobs in the future.

"He likes to watch but most of the time he will listen to songs or play games. He can play games. So if he does something that I request him to do, I will give him to use the phone like a reward. A reward for him." (Yana, 233)

ASD children's behaviour differs from typical children. They are perceived as more vulnerable and need extra care. This vulnerability is due to their inability to engage in interpersonal communication with other people (National Institute of Mental Health, 2018). Hence, they might not be able to listen and follow instructions. The participants explained how being strict and exercising tight supervision helped them control their children to regulate their behaviour. Yana explained how being firm and stern towards her child enabled her to regulate his behaviour. She emphasized using suitable parenting methods to ensure her son understood the situation and behaved well.

"'Ah' yes because my son tends to scream a lot until nighttime, noisy right so he gets scolded and he understands now. Once I raise my hand like that he knows that we won't hit him. He will get it right." (Yana, 277)

Similarly, Hawa was assertive and firm towards her son. She understood her child's behavioural pattern and had to be strict by not allowing him to attend to the mobile phone for too long. She emphasizes her son's needs before ensuring he has an ASD supportive environment to promote positive growth.

"Because his father care for him so much, for me no, I need be stricter. Like that because if he plays the mobile phone for too long, he will have tantrum. He always tantrum if he plays for too long." (Hawa, 348)

*Being equal to all children*

While some mothers believed that special treatment should be given to a child with ASD, others felt that equal treatment should be implemented instead. The participants in this research did not perceive ASD children as special children that result in individual therapy. They believed that treating all children equal was the way to ensure that their ASD child became independent. These made sure that their child felt the same, leading to maintain their self-esteem. Nurul emphasized how she treated all her children equally regardless of their condition. This fairness was to avoid biases and train her daughter to live within society's norms. In other words, she tried to help her child to adapt to their environment and enhancing independent living.

“I don't compare normal children with special children. For me they are the same. We can't say that normal children should do more than OKU children no not that way.” (Nurul, 99)

“Yes for me, I told them that my style with my daughter is that if she does anything wrong, I will scold her. Whatever she does, I will stare and keep an eye on her. This is because she is going to live with people that are normal.” (Nurul, 415)

Similarly, Hawa explained how she tried to observe the situation and realised that her son's condition was not far off from typical children. Hence, these lead her to adapt to her son and perceive him as an average child in the end.

“In the beginning, when we are not used to take care of these types of children we will feel stress. ‘Mm’ but as time goes by I feel okay. I treat my son same as normal children even with his current condition.” (Hawa, 68)

Thus, parenting a child with special needs varies according to the parents' knowledge, skills, and supports. Mothers should consider the context and condition of the child, whereby the needs of children with ASD differ from one to another.

**Discussion and Conclusion**

This research seeks to understand the life experiences of low-income mothers with ASD children and how they make sense of those experiences. The approaches for this research were adopted using the IPA method whereby each participant's experience was analysed in-depth in determining how they make sense of those experiences. The results were presented based on the children's condition and the context of the mothers' life. The findings were differentiated from the existing knowledge through which the development of themes was based on the participants' verbal accounts.

The main themes discovered in this research reflect the changes in roles and daily routine of the mothers. The themes specifically highlighted mental preparation, trust issues, career adjustments, and changes in parenting approaches, including high involvement in child's daily life, employing creative parenting in behavioural control, and being equal to all children. Mothers were concerned with their own lives in terms of mental preparation for accepting their child's diagnosis. Those who were not mentally prepared and had no knowledge about autism found it is challenging to take their child's condition. The mothers also highlighted trust issues and career adjustments. They had difficulty in finding trustable child care that understands the needs of ASD children and therefore adjusted their career life to obtain flexibility for themselves and their child. Parenting approaches were also discussed, and the mothers addressed the changes they had to make in raising their ASD child. Emphasis was given on the importance of being highly involved in the child's daily life, including education and healthcare. They were also creatively adjusting their approaches to controlling their

child's behaviours, such as using mobile phones to distract them, especially in public settings. Tight supervision were also implemented to ensure the development and safety of their children. They treat their ASD child like other children so that their child can survive independently like other children.

Based on this research, low-income mothers require substantial support from all systems, including family, peers, education, public and governmental systems. While previous literature highlighted the economic challenges faced by low-income communities, such as financial constraints (Arshat, Pai & Ismail, 2018), this research shows that economic conditions were the least concerns to mothers with ASD children. These findings reflect the actual experiences faced by mothers in the low-income community. Mothering children with special needs require adequate knowledge and social support, especially from credible daycare centres, to take care of their child. The available facilities are limited, and they faced difficulties acquiring accurate knowledge about ASD diagnosis and treatment options. This limited knowledge of ASD hinders them from providing their child with proper care. They failed to identify reliable sources and support they seek. Hence, these mothers need help from relevant people and organizations to ensure they are given information about their child's condition and future planning.

In improving the lives of mothers with ASD children, several recommendations were proposed to various stakeholders. These recommendations include providing parents with appropriate education courses. Parent education refers to an educational effort to facilitate parents' behaviours that influence positive development outcomes in their children (Prata, Lawson & Coelho, 2018). It benefits both the ASD child and caregiver by enhancing insights and knowledge on the individual child, enabling the caregiver to incorporate therapy into the child's environment as well as improving communication skills and social behaviour (Prata et al., 2018). The training should also be given to lower-income families, as many mothers face issues, such as lack of knowledge in parenting ASD children. Both formal and informal education should be given to mothers with children with ASD for the best results. Providing parenting knowledge is vital and will help to improve the lives of both parents and children. It will also solve many parents' dilemma. This finding is similar to a previous study by Ying et al. (2018), which proposed community health programs for parents to equip them with knowledge on early symptoms of ASD and intervention options. Additional information on parenting tips, especially on controlling a child's behaviour, may be added to enhance parents' skills in complementing therapy treatments for the developmental milestones progress of their children.

While this research offered insight into the lived experience and meaning-making of mothers with ASD children, future research should also focus on fathering in the child's life. Hence, this research will provide a comprehensive view of ensuring the well-being and development of the child.

To conclude, this research may contribute to the development and verification of existing research on ASD matters. In regard to the economic challenges faced by these parents, previous research by Chu et al. (2018) indicated that parents faced financial constraints, particularly in terms of treatment and therapy. However, this present research shows that there are adequate treatment facilities for their ASD child. The mothers are more concerned about raising their children to be able to live independently. Thus, they seek more reliable resources and information, which will enable them to parent their child more effectively.

On the other hand, this research complement and verifies the aspect of career development. Mothers of ASD children had to make adjustments in their careers. They usually either quit

their full-time jobs or vent into any jobs with flexibility to attend to their child's needs. These jobs also include starting up their own business to continue contributing to the family economic needs while supplementing the government's initiative in Malaysia towards a gig economy. On the other hand, some mothers opt to become full-time caregivers to their ASD child (Lim, 2015) as they cannot trust other caregivers in taking care of their child. Overall, this research provides a better understanding of the needs of mothers with ASD children by analysing their mental and emotional condition.

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