





THE CHALLENGE OF MANAGING CHILDREN WITH AUTISM FROM FATHERS' PERSPECTIVES

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ABSTRACT

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It is widely known that parents of children with autism encounter various challenges in raising their children. Reports related to previous studies indicated that these parents experienced higher stress compared to parents of typical children. However, the study pertaining to fathers of children with autism has not been explored, and it has left a gap in the study of parenting in relation to children with developmental problems, especially autism. Therefore, this study was conducted to understand the challenges faced by fathers in managing children with autism. This study used semi-structured interviews as a research tool and sampled five fathers of children with autism between the ages of four and nine years of age. The study was conducted in Langkawi Island, Kedah. The results found that fathers have to cope with challenges from an emotional aspect in accepting and managing children with autism.

Contribution/Originality: The paper's primary contribution is the finding that fathers experience emotional challenges while caring for their children with autism, which is similar to mothers' experiences reported in past studies.

1. INTRODUCTION

Based on the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), autism refers to deficiencies in communication and aspects of social interaction, tendencies towards restrictive repetitive behaviors, and strong interest in or obsession towards an activity (American Psychiatric Association (APA), 2013). According to the Ministry of Health of Malaysia (2014), autism is described as a developmental disorder that can be observed during childhood through communication, social skills and behavioral problems. The prevalence of autism in Malaysia is about 1.6 in 1000. Meanwhile, in the United States, the number of children with autism is 14.7 in 1000 (1 in 68). Studies reveal that boys are four times more likely to have autism than girls. The cause of autism remains unknown; hence, a cure is still to be found (Center for Disease Control and Prevention, 2019).

Generally, being a parent is stressful. However, being a parent of a child with autism is even more challenging, especially in countries that lack support services (Kartini, Cornish, Park, & Golden, 2015). Raising children with developmental disabilities requires parents to provide extensive care for their children, and past studies have reported that parent of children with autism experience emotional challenges such as stress, depression, and high

anxiety among other health-related issues (Azlina, Ahmad, Oon, & Razali, 2008; Cridland, Jones, Magee, & Caputi, 2014; Hayes & Watson, 2013; Kartini, Liaw, Cornish, Park, & Golden, 2016). Parents also face financial issues in raising children with autism. Previous studies reported that these parents encounter financial problems twice as much as parents of typical children (Koegel & LaZebnik, 2004; Muralidharan, 2016; Solomon, 2012), and in addition, they have to deal with the stigma surrounding mental illness in society (Bashir, Bashir, Lone, & Ahmad, 2014; Cashin, 2004; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Glass, 2001; Gray, 2002; Hoogsteen & Woodgate, 2013; Kartini, Liaw, Cornish, Park, & Golden, 2016; Ludlow, Skelly, & Rohleder, 2011).

Previously, research on early childhood development mainly focused on the mother rather than the father due to the traditional understanding of a father's role as the breadwinner in a household. However, in line with lifestyle changes of society in the twenty-first century, the focus of research also realized the positive influence of fathers' involvement in the lives and education of children (Tadi, 2018). Numerous studies in recent years have proven the importance of fathers' roles in early childhood development, including improved school performance, self-confidence and behavior (Flippin & Crais, 2011; Ihmeideh, 2014; McFadden, Tamis-LeMonda, & Cabrera, 2011; Peterson, 2014). Studies also reported that children who have a good relationship with their father have noticeably fewer negative experiences in life, such as depression and behavioral issues. In fact, they are more likely to exhibit good social behavior (Rosenberg & Wilcox, 2006).

Therefore, this study aims to explore the challenges faced by fathers in managing children with autism. The involvement of a father is considered significant in the lives of typical children as well as children with developmental disorders such as autism. In addition, fathers play an important role in the psychological development of children with disabilities (Ahmad & Dardas, 2015). The objective of this study is to explore the emotional challenges faced by fathers of children with autism.

1.1. Role of Fathers

Being a father is regarded an achievement by most men. It is rewarding, yet stressful at times (Chin, Daiches, & Hall, 2011; Garfield, Isacco, & Bartlo, 2010), and it is more complicated to be a father to a child with autism (Hannon, 2014; Hannon & Hannon, 2017). Many scientific studies on fatherhood and children with autism have been documented, for instance, what the relationship is like between a father and a child with autism (Gerdts, Bernier, Dawson, & Estes, 2013; Itzhak, Lahat, & Zachor, 2011; Janecka, Rijdsdijk, Rai, Modabbernia, & Reichenberg, 2017). Therefore, in order to continue the study on fathering children with autism, we need to understand their challenges and experiences in managing and raising their children.

Previous studies have shown that fathers experience emotional challenges in managing their children. For instance, a study conducted by Giallo et al. (2015); Griffith et al. (2011) and Hastings and Brown (2002), reported a significant proportion (between 15% and 33%) of fathers to children with autism experienced a number of symptoms of psychological stress, such as tension, anxiety, fatigue, sadness, depression and anger. Moreover, according to Herring et al., (2006), the emotional wellbeing of fathers who have children with autism is more at risk when compared to fathers of typical children. Normally, fathers will start to feel the emotional challenges as soon as they receive their child's diagnosis. Past studies have stated that most fathers went through a denial phase and were unable to accept the diagnosis of their child's autism for quite some time (Hartley et al., 2010; Hoogsteen & Woodgate, 2013).

Consequently, there are many challenges concerning the emotional aspects faced by the father of a child with autism. For example, they experience anxiety, fear, anger, sadness, denial, tiredness, stress and worry (Ahmad & Dardas, 2015; Burrell, Ives, & Unwin, 2017; Cheuk & Lashewicz, 2015; Fryer, 2015; Hannon, Blancard, & Storlie, 2019; Paynter, Davies, & Beamish, 2017). In a qualitative study by Burrell et al. (2017), fathers reported experiencing feelings of anger more than feelings of sadness. This anger arose when they felt unable to control difficult situations at home due to the recurring behavioral problems and stubbornness demonstrated by their child.

However, guilt and feelings of sadness arose when they realized that they had reacted angrily and lost control of their emotions (Burrell et al., 2017; Fryer, 2015).

Stress is another emotional aspect experienced by fathers in managing children with autism. According to a report by Ahmad and Dardas (2015), they found that the stress experienced by a father stems from various aspects, one of which is the difficulty in understanding and controlling the behavior of their children. Children with moderate and severe autism are often reported to cause stress to fathers (Davis & Carter, 2008; Herring et al., 2006). In addition, they also stated that they faced emotional and physical exhaustion in managing their children. The fathers who contributed to studies conducted by Paynter et al. (2017) and Cheuk and Lashewicz (2015) expressed that they suffered from exhaustion as they did not have enough time to manage children as well as other matters.

1.2. Problem Statement

In general, parents share responsibilities and they both have roles to play in raising and managing their children. However, it has become the norm for mothers to play a greater role in taking care of children's needs (Meadan, Stoner, & Angell, 2015). This is evident in previous studies relating to families with children who have developmental problems, which were more focused on mothers rather than fathers (Braunstein, Peniston, Perelman, & Cassano, 2013; Bromley, Hare, Davison, & Emerson, 2004; Tomanik, Harris, & Hawkins, 2004). Although there have been efforts made in the past by researchers to understand the experience from a father's perspective, it is difficult to explore as they considered the fathers as difficult to approach, invisible parents, and "shadows" in the family system (Carpenter & Towers, 2008), thus leading to a lack of information regarding the challenges, experiences, and effects on fathers who have children with autism (Nicholas, 2018).

However, previous research has gathered some information on how fathers engage in the care and management of children with autism. For example, a study entitled "The Fathers of Autistic Children" by Eisenberg (1957) is one of the preliminary studies relating to fathers of children with autism. He noted that the 'father is not a remembered figure', as through literature review, he found that only three out of 26 studies that involved fathers had been published at that time. Hastings et al., (2005) conducted a study on the differences in experience from a psychological aspect between mothers and fathers, while Elder, Valcante, Yarandi, White, and Elder (2005) studied the role of fathers in interventions. In addition, there were also studies on fathers of children with autism and the impact of support groups on stress, depression, isolation, and satisfaction in marriage conducted by Elfert (2014). He distinctly stated at the end of his research, that although the number of studies on the experience of fathers of children with autism is increasing every year, these studies are still focused on mothers as the main research participants. He also stressed that more studies focusing on the fathers need to be conducted, as there is still a of information required.

The above are statements from previous research on fathers in western countries. In Malaysia, there were studies conducted on both mothers and fathers. The latest studies were published in 2019 by Kartini et al., (2016); Muhammad & Nurul, (2019), who each studied the risks and challenges faced by parents of children with autism. The studies conducted were still from mothers' perspectives and did not focus on fathers only. Undoubtedly, there were studies that involved fathers, such as the ones conducted by Chu, Siti, McConnell, Tan, and Singh (2018); Mohd and Nur (2018); Muralidharan (2016), however, studies that solely focused on the perspectives of fathers are still very limited in Malaysia.

It is important to explore this issue, as the information regarding the challenges and experiences encountered by fathers in managing children with autism still requires much study. Furthermore, past studies pertaining to fathers of children with autism were mostly from the perspective of those in western countries. The challenges and experiences faced by fathers may differ based on background and cultural factors (Meadan et al., 2015). Hence, the understanding around the feelings and experiences of fathers of children with autism in Malaysia can be observed

and documented to investigate if they also encounter challenges from emotional and psychological aspects as the mother do. The purpose of this study is to explore the challenges, specifically on the emotional aspects, faced by fathers of children with autism to close the gap on previous studies.

2. METHODOLOGY

A qualitative research approach was employed as it fits the main purpose of this study, which is to explore the challenges faced by fathers in managing children with autism. This approach deeply probes (Silverman, 2013) to understand social problems in real-life situations through the views of the study participants (Creswell & Poth, 2018). Meanwhile, a phenomenological research design was utilized to explore the challenges experienced by the study participants in managing their child with autism. Phenomenology is used to understand when certain phenomena occur in the lives of the study participants with the aim of discovering their true causes (Creswell & Poth, 2018; Englander, 2012; Moustakas, 1994).

2.1. Study Sampling and Location

Snowball sampling was used in this study to recruit participants; the interviewed participants suggest others who also meet the research criteria (Creswell, 2013; Merriam & Tindell, 2016). Based on the context of this study, the participants are biological fathers who have children between the ages of three and nine years old who were officially diagnosed with autism between the ages of two and four years old. All participants are located in Langkawi Island, Kedah. Kedah was chosen as the study location because, based on literature review, the researcher found that no study exists on fathers, or parents, of children with autism in the northern part of peninsular Malaysia. Therefore, to fill this gap, the researcher chose to conduct this study to understand the challenges of fathers in this particular region.

2.2. Data Collection Procedures

Semi-structured interviews were used as the data collection method for this study. This method allows researchers to gather information about the experiences encountered, emotions felt, and the participants' perspectives on the topic being studied (Bloomberg & Volpe, 2019). The interview questions were adapted based on a study conducted by Darden (2019) regarding the role of African fathers in the United States in raising children with autism. The questions went through a translation process to ensure they conveyed the same meaning. Next, the researcher developed an interview protocol to facilitate the interview process with the study participants and obtained the validity of the protocol from three experts, two experts in the family field and a methodologist. Prior to the interview, the researcher conducted a pilot study on a father of a child with autism who met the required criteria. All participants were asked to read and sign letters of consent before the study began. All interviews were conducted face-to-face, and the sessions lasted for 40–80 minutes. Study participants were also informed that, throughout the interview process, audio recordings would be made for transcription purposes by the researcher.

2.3. Data Analysis Procedures

All interviews were transcribed verbatim, re-read, and compared to maintain the meaning of the interview. The researcher then focused on a coding selection method in order to summarize the data resulting from the interview (Miles, Huberman, & Saldana, 2014). A codebook was also prepared as a guide to analyze the interview data. The encoding book systematically recorded the codes that appeared from interview results and organized them into multiple categories (Saldana, 2015). After the coding process, the interview transcripts were carefully analyzed using a thematic analysis method. The purpose of this thematic analysis was to identify and summarize themes in the interview data (Ryan & Benard, 2000). In addition, through thematic analysis, it explains the reality and meaning of study participants' daily lives and acts as a tool that focuses on real life experiences that occur in society.

2.4. Validity and Reliability

The reliability aspect of a qualitative study is crucial as it helps to maintain accuracy in the interpretation and analysis, and preserves the findings of the study (Creswell & Poth, 2018). Therefore, in order to improve the reliability of this study, the researcher consulted experts to check the accuracy of the data codes of the interview transcripts. The experts reviewed the codes from all five transcripts and reviewed the themes and sub-themes extracted by the researcher. Two themes required improvement to ensure they achieved the actual meaning as suggested by the experts.

3. FINDINGS

All study participants are biological fathers of children with autism and have signed the consent form and understood that confidentiality and anonymity will be maintained.

Table 1. Demographic report of study participants.

Study Participant Code	Age	Education Background	Occupation	Marital Status	Age of Child	Age Diagnosed with Autism
01	36	STPM	Police officer	Married	7 years	3 years
02	53	Masters	Hotelier	Married	7 years	3 years
03	34	SPM	Self-employed	Single father	7 years	3 years
04	32	Bachelor's Degree	Teacher	Married	3 years 2 months	2 years 8 months
05	32	Bachelor's Degree	Teacher	Married	7 years	2 years 6 months

Table 1 shows the demographic report on the background of all five study participants. Based on the report, four of the five study participants were in their early 30s, and one in their 50s. Three of them have university education backgrounds, one with the Malaysian Certificate of Higher Education (STPM) and one with the Malaysian Certificate of Education (SPM). Two of the participants work as teachers and the other three have varying occupations. In addition, one participant is a single father who is solely responsible for the care of his child, while the other four are married. Last, four out of five children are seven years of age, one is three years old, and three of them were diagnosed with autism at the age of three and another two at 2 years old.

Based on the analysis of the study participants' interview transcripts, two themes were extracted, namely *emotions towards acceptance of autism* and *emotions towards management of autism*. Table 2 shows the theme results yielded from the interview questionnaire.

Table 2. Summary of study findings.

Study Questions	Theme	Sub-theme
What is the challenge from emotional aspects faced by the fathers of children with autism?	Emotion towards acceptance of autism	Calm upon knowing that their child has autism
	Emotion towards management of autism	Resign and accept that their child has autism Be patient and remain positive Losing emotional control Emotionally affected as a father

Theme 1: Emotion towards acceptance of autism

3.1. Calm Upon Knowing That Their Child Has Autism

Two out of three fathers said that the first reaction when their children's specialist told them that their children had autism was calmly accepting the diagnosis. Based on their tone of voice, facial expressions, and body language

when talking about their initial reaction after their child's diagnosis, they appeared calm, and their facial reaction or body language did not indicate that they were frustrated with the diagnosis.

"I am a person that...I do not get jumpy that easily. However, when I knew about the condition, OK, he has problems. Therefore, my approach is, I would like to find out what the solutions are. That's all."

(Study participant 01)

However, two fathers recalled that their initial reaction was a feeling of sadness upon being given the diagnosis. Their tones of voice were rather low showing that they felt down when it was confirmed.

"I'm sad. Just sad. (Heavy breathing) Why do I receive such a test? A child with such a problem, it is pitiful, I felt rather sad at that time. Was thinking what did I do wrong? What is not right? Maybe it was something that I did. Perhaps. Hmm."

(Study participant 03)

3.2. Resigned and Accepted That Their Child Has Autism

All fathers said that they accepted their children's autism diagnosis when asked about their feelings and acceptance.

"I said that I would accept this fate, same goes with my wife, and we resigned. Because...why would we go against God's will, what's the point?"

(Study participant 02)

"I was more towards resigning. So, when it was confirmed, personally, I already accepted it at that time."

(Study participant 05)

3.3. Be Patient and Remain Positive

When asked how they handled their emotions regarding their child's diagnosis, four out of five fathers stated they tried to be patient and remained positive in dealing with their emotions.

"So, we just try to be patient."

(Study participant 01)

"Because God gives such a test to us, as people always say, to make us realize and have patience. This is part of life. We can't go against God's will."

(Study participant 02)

"I just remained positive, that's it."

(Study participant 06)

Meanwhile, one father stated that he handled his emotions at that time by finding solitude.

"I was like; at that time ... I didn't share with anyone then. I just kept to myself. Hmm Yes. I was in isolation."

(Study participant 03)

Theme 2: Emotions towards the management of autism

After all the fathers had shared their experiences, they continued to talk about the emotional challenges in managing their children with autism. This theme explains about the challenges that the fathers experienced from emotional aspects when managing their children. There are two sub-themes: losing emotional control and being emotionally affected as a father.

3.4. Losing Emotional Control

Four fathers shared that anger was a challenge they experienced. The feelings of anger arose when they encountered unpredictable behavioral problems.

"There are times when he will make us feel angry, right. It's resentful."

(Study participant 01)

"Then he will do the things that we forbid. He will stop for a moment, or a while, but then he will just continue to repeat. A minute or two later, he will repeat the same thing again. Yes. Sometimes, I do feel angry."

(Study participant 03)

Three fathers also felt stress when managing their children.

"So, the problem is to find him a doctor that will be able to make him sleep. However, the problem arises after he wakes up. To take care of him is another issue, really. Afraid that he will open the bandage later, that is a problem. That's very critical and challenging for us, now we feel the pressure on how to continue".

(Study participant 02)

In addition, three parents shared that they felt tired when managing their children.

"When I arrived home late and feeling tired, my wife is also exhausted from managing my child who was active at home, and she too needed my help to take care of our child. Coming home late, I found myself feeling entirely drained emotionally in order to manage things in school. And at home, the child wanted to play with us".

(Study participant 04)

Patience was the other aspect mentioned by three fathers as another emotional challenge. They shared that they knew they needed to be patient with their children.

"To face the challenge, we need to have lots of patience. Be OK with the child behavior. These children with autism, we cannot predict their emotions. Sometimes, the child will suddenly scream. At times, the child will throw a fit. At that point, it requires lots of patience. If we are not patient, we are not able to take care of this child with autism."

(Study participant 02)

3.5. Emotionally Affected as a Father

This sub-theme describes how the presence of a child with autism affects the paternal role of study participants. Three fathers stated that the presence of their child with autism affects their role as a father because they need to balance their responsibilities as a father to their children with and without autism.

"When a child is considered special, sometimes we pay more attention to him. Even my second child, he is only 6 years old. However, he did mention it. Sometimes, he expressed, "You always scold me, but not my brother. And I obey". That is how he described it. So, when he says things like that, we do feel emotionally affected."

(Study participant 01).

"I need to attend to the elder brother much more. Hmm. I need to teach him more often, even during mealtime, I need to pay more attention to the brother (with autism). He (younger brother) is able to eat by himself. He can eat on his own; he can manage and take care of everything."

(Study participant 03)

"In general, when he has autism, he interferes in terms of us wanting to manage other children."

(Study participant 05)

In comparison, the other two study participants said that the presence of their child with autism did not affect their role as a father.

"Maybe because he is our first child, and I am still learning (laughing) to be a dad, right. So, when he was diagnosed with autism, I believe that in a way he has helped me to be a more understanding person."

(Study participant 04)

"No, I'm OK. When we knew that he has autism, my other children understood. Anyway, my other children are all grown up; they are 23 and 15 years old."

(Study participant 02)

4. DISCUSSION

Results of the study found that fathers do encounter challenges from an emotional aspect in managing their children with autism. Four out of five fathers shared the same sentiment that they did lose control and scolded their children, which happened when they needed to confront the unpredictable and problematic behavior. Behaviors, such as having to be told the same thing repeatedly, tantrums, and having to attend to the needs and attention of children with autism, left these fathers unable to contain their emotions and scolded their children with autism. This is in line with results from previous studies by [Burrell et al. \(2017\)](#) and [Fryer \(2015\)](#) that found that fathers experienced feelings of anger during situations at home caused by their child with autism.

The study found that fathers also feel stress in managing children with autism. Just like the anger experienced by fathers, the causes of stress are due to behavioral problems and the pressure to provide the best care and fulfill the needs of their children. This finding is supported by [Ahmad and Dardas \(2015\)](#); [Davis and Carter \(2008\)](#) and [Herring et al. \(2006\)](#) who reported that the behavioral issues of a child with autism vary according to their spectrum level, and become a major cause of stress for fathers. A study involving parents of children with autism in Malaysia stated that 90.4% of parents suffer from stress and 53.8% showed psychological problems ([Azlina et al., 2008](#)). Therefore, it is evident from the findings of this study, that fathers also experience stress in managing children with autism, similar to those faced by mothers as stated by previous studies ([Bekhet, Johnson, & Zauszniewski, 2012](#); [Hoogsteen & Woodgate, 2013](#); [Khanna et al., 2011](#)).

Additionally, fathers in this study shared that they experienced exhaustion. This occurred when they did not have sufficient time to manage a child with autism, and other family members as well as other matters in their daily lives. These fathers talked about their children with autism having recurring behavioral problems, being unable to manage without the help of another person and requiring constant training to ensure that they are able to do things related to self-management. The study findings concur with previous studies in which fathers stated that they feel tired because they do not have enough time to manage other things as well as themselves ([Cheuk & Lashewicz, 2015](#); [Paynter et al., 2017](#)).

It was also discovered that fathers are affected by the presence of their child with autism. They explained that having a child with autism affects their role as a father because they also need to balance their responsibilities with their typical child, career, and other life matters. Although this finding did not appear in the literature review, it is supported by the research by [Darden \(2019\)](#) and [MacDonald and Hastings \(2010\)](#). In their research, they reported that the challenge of trying to balance additional work and family responsibilities had caused fathers to be emotionally affected as the head of the family, thus it is evident that having a child with autism put more pressure on a father's role.

In order to face the emotional challenges in managing their children with autism, the study also recognized that being patient helped the fathers to address these challenges. Being patient is how the fathers deal with the behavior of their children, and their confidence in God's will helps them in this respect, however, this finding is not supported by any studies in the literature review section. This may be because past studies pertaining to fathers are mostly from the perspectives of those in western countries. Nevertheless, this finding is supported by several studies involving the participation of mothers and both parents on raising and managing children with autism in Asian countries. These studies found that having faith in God, and their respective religions, helped them in addressing the challenges of managing children with autism ([Chong & Kua, 2016](#); [Jegatheesan, Miller, & Fowler, 2010](#); [Resurreccion, 2013](#)).

In relation to fathers' emotional acceptance of autism, the findings show that fathers were calm when their children were given the autism diagnosis. Although many previous studies have reported that fathers experienced a denial phase ([Hartley et al., 2010](#); [Hoogsteen & Woodgate, 2013](#); [Myers, Mackintosh, & Goin-Kochel, 2009](#)), this study showed that fathers were calm in accepting the fact that their children have autism. The findings agree with research by [Darden \(2019\)](#), in which fathers said they did not experience the denial phase and were more open in

trying to assist their children after receiving the autism diagnosis. Fathers in this study were much more willing to accept the condition of their children. This finding corresponds with the study by Fryer (2015), which also reported that fathers expressed acceptance of their child's diagnosis and stated that feeling angry or denying the diagnosis would stop them from feeling calm.

5. CONCLUSION

The main purpose of this phenomenological study was to explore the challenges of fathers in managing children with autism. It is evident that fathers experience challenges from the emotional aspects similar to mothers in managing children with autism. This study also gives a detailed understanding around the challenges that emotional aspects bring. The study findings discovered two main themes when exploring the challenges on the emotional aspects, namely emotion towards management of autism, and emotion towards acceptance of autism. The fathers emotionally lost control due to the behavioral problem of children with autism, and it affected their roles as fathers. Nevertheless, fathers to these children remain positive and accept the fact that their children have autism. All these challenges have given more meaning to them as heads of families in their efforts to provide the best for their children.

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