

# Emotional and Financial Challenges of Raising Children with Autism: The Experience of Fathers in Malaysia

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## Abstract

This study explored the emotional and financial challenges faced by fathers in Malaysia when raising and managing children with autism. This qualitative study adopted a phenomenological research design and involved a total of seven fathers in Kedah, Malaysia. The sampling method used in this study was purposive sampling. This study used the interview method entirely as the data collection approach. Meanwhile, semi-structured interviews were conducted to obtain data from participants. The results showed that the fathers of children with autism faced numerous emotional and financial challenges in handling children with special needs. The findings provide more direction and insights for future research to study and explore various aspects of parenting children or individuals with autism. The outcomes also make it necessary for the relevant authorities to enhance the facilities and provision for better management of these children.

**Keywords:** Autism, Constraint, Involvement, Paternal.

## Introduction

Autism refers to neurological disorders which affect an individual's life and their immediate family members. The American Psychiatric Association (2013) defined autism as a neurodevelopmental disorder involving social interaction, social communication, and repetitive and restricted behaviour. The onset of autism can be identified when children are experiencing delayed oral and social skills development. The obvious characteristic of autism in early childhood is a lack of interest in social interaction in their first year (Paul and Kimberly, 2011). Additionally, during a study, such children did not show interest in conversing with others, frequently clapped their hands, had no eye contact when interacting, followed stringent daily routines and had 'a could not care the least' attitude about others' perceptions of them (Mislán et al., 2012; Frith, 2013).

Autism is a disability which affects parents who take care of their children (Ooi et al., 2016). Exacerbating this is the current lack of medication that can cure individuals with autism (Idris et al., 2017). This clearly poses complex challenges to parents in managing and educating children with autism. Multiple research has shown that the parents of these children experienced higher stress levels than parents who managed typical children (Baker, 2010). Parents of children with autism face significant difficulties after the children have been confirmed through diagnosis (Corcoran et al., 2015; DePape and Sally, 2015).

Before the diagnosis, parents usually perceive their children to be the best, despite their differences. However, after the diagnosis, these parents must accept the fact that their children will have to live with a disability that will directly affect their daily lives. After their children have been diagnosed with autism, these parents tend to experience emotional instability (Olsen, 2010). They must learn how to address and adapt to the challenges imposed on their families (Desai et al., 2012; Poslawsky et al., 2013). The immediate life changes that affect the parents of children with autism are wide-ranging. They include coping with the need to make changes to their daily routines and, at worst, parents may have to make some personal sacrifices in order to balance life with family members, partners and employment (Pullen, 2009; Olsen, 2010).

Raising a child with disabilities or special needs also requires highly specialised and personalised care. One of the challenges is experiencing prolonged periods of stress (Dyson, 1997). Past research has highlighted that parents of children with autism face high levels of stress, depression, anxiety and other health issues (Hayes and Watson, 2013; Cridland et al., 2014; Illias et al., 2016). Divan et al (2012) concurred in their research, finding that these parents frequently face various emotional and health problems, including fatigue, body aches and sleeping problems.

Furthermore, the financial challenge involved is a major concern for parents of children with autism. It is generally known that such children need to attend therapy sessions or specific treatment to enhance or develop certain skills that are essential for their development. These forms of therapy or treatment incur high costs which can impose serious long-term financial burdens on the parents involved (Falk et al., 2014; Saunders et al., 2015; Paynter et al., 2017). Most of these parents also sacrifice time and energy stabilising their financial circumstances in attempting to fulfil their children's needs (Lee et al., 2017). Related research also supported this finding, explaining clearly that parents of children with autism bear easily double the challenges in terms of finance compared to parents of typical children (Solomon, 2012; Cheuk and Lashewich, 2015; Muralidharan, 2016).

For years, it has become unexceptional for mothers to play a more dominant part in the caring for and upbringing of children (Meadan et al., 2015). Past research on the parenting of children with developmental problems has focused more on the challenges and experiences of mothers compared to fathers (Bromley et al., 2004; Braunstein et al., 2013). Accordingly, the roles, understanding and experiences of fathers with children facing developmental problems have received less attention and less information on this subject is available (Meadan et al., 2015). This is mainly because fathers are individuals who are less approachable (Carpenters & Towers, 2008).

In Malaysia, research on family issues and parenting mainly involves parents as a couple (Muralidharan, 2016; Chuet al., 2018; Mohamad and Rosdi, 2018). However, a limited body of research focuses specifically on the perspectives of only the father of a special needs child. Therefore, this research has been conducted to explore and understand the challenges experienced by fathers in handling children with autism. This research also ensures that research is now available on the involvement and experiences of such fathers in Asia and specifically Southeast Asia, which encompasses mainly developing countries (Ilias et al., 2008; Clark et al., 2012; Daley et al., 2013; Norbury and Sparks, 2013; Neik et al., 2014; Golden and Liaw, 2015). This was deemed necessary because the challenges experienced by a father may differ according to their backgrounds and cultures (Meagan et al., 2015). Furthermore, most related research had been based on the challenges experienced by fathers in handling children with autism in the Western context. Hence, this study documents a detailed understanding of the challenges experienced by fathers in handling children with autism in the Malaysian context. Hence, the aims of this study are:

- a) to investigate the emotional challenges experienced by fathers in handling and raising children with autism.
- b) to investigate the financial challenges experienced by fathers in handling and raising children with autism.

### **Methodology**

This qualitative study used a phenomenological research design. A total of seven participants were involved in this study and the purposive sampling technique were used to select the participants. Purposive sampling was chosen to ensure that the data collected were in-depth and meaningful in relation to the issues and to accomplish the study objectives (Meriam and Tindell, 2016). The criteria used for selecting the participants were: i) a father who has a child with autism aged three to nine years old; and ii) the child had been diagnosed with autism when aged between two and three years old. All the participants involved in this study were located in Kedah, Malaysia. Kedah is the northern part of Peninsular Malaysia and it was chosen as the location for this study because no past researches found to be performed on fathers or, generally, parents' experiences of children with autism.

This study utilised a semi-structured interview protocol as it offered flexibility when framing and ordering the questions (Merriam & Tisdell, 2016). The semi-structured interview technique enabled face-to-face interactions on a one-to-one basis, which helped considerably to avoid bias in the data collected. There were ample opportunities to reduce the inhibitions of the participants so they could contribute important and in-depth data for this study. This facilitated the creation of meaningful statements that constructed the essence of the information and provided a comprehensive and realistic understanding of the phenomenon through a combination of open-ended and closed-ended questions, as well as question tags.

The researcher transcribed all interviews verbatimly, re-read and compared them, in order to retain the interviews' meaning. Then, to summarise the data from the interviews, the researcher concentrated by doing the coding selection process (Miles et al., 2014). Hence, a codebook was prepared to guide and analyse the data from the interviews. This codebook was systematically recorded all the codes emerged and were organised into categories (Saldana, 2015). To analyse the data, this study was using a thematic analysis approach. Thematic analysis also identified and extracted themes from the interviews of the study

participants. The purpose of this thematic analysis was to summarise the interview data into themes (Ryan and Bernard, 2000). In addition, by using thematic analysis, it enables the researcher to capture the meaningful data about participants' real-life experiences. The data analyses for this study were presented in the form of narratives. The narratives explained the information as divulged by the participants.

Reliability or trustworthiness is crucial aspects in qualitative research as it supports accuracy, lead to better understanding and at the same time preserve the study's discovery/findings (Creswell and Poth, 2018). Hence, the researcher undertook discussions with experts and they had reviewed the codes to ensure the accuracy of the codes from the interview transcripts. In addition, the study's themes and sub-themes extracted by the researcher also had been reviewed by the experts. There were two themes that needed to be improved, so the corrected themes reflect the meanings suggested by the experts.

### **Results**

Table 1 refers the demographic backgrounds of all seven participants in this study. There was one participant in his 50s while the other six were in their early 30s. Besides that, five of the participants had a degree, one had the Malaysian Certificate of Higher Education (STPM) and one had the Malaysian Certificate of Education (SPM). Two of them worked as educators, meanwhile the other five had different occupations. One of the participants was a widower who took sole care of his son, while the rest were married. The participants' sons age ranging from three to nine years old. There were five of the children were diagnosed with autism at the age of three, and the other two were diagnosed at the age of two years old. Based on the analysis results, two themes emerged in terms of emotional and financial challenges.

Table 1

*Demographic information of study participants*

<i>Study Participant (Study Participant Code)</i>	<i>Age</i>	<i>Education Background</i>	<i>Occupation</i>	<i>Marital Status</i>	<i>Age of child</i>	<i>Age diagnosed with autism</i>
01	36	STPM	Police	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	36	Masters	Administration and Diplomatic Officer	Married	9 years	3 years
05	32	Bachelor's Degree	Teacher	Married	3 years 2 months	2 years 8 months
06	32	Bachelor's Degree	Teacher	Married	7 years	2 years 6 months
07	35	Bachelor's Degree	Teacher	Married	5 years	3 years

**Emotional Challenges**

Two themes emerged in relation to the emotional challenges, namely (i) the fathers' emotions upon discovering the results of the diagnosis, and (ii) the fathers' emotions in dealing with their children.

***The Fathers' Emotions when the Diagnosis was Confirmed******Calm when informed about their child had diagnosed with autism***

Five of the fathers explained that they were calm when the diagnosis had been confirmed. The five fathers claimed that they had already had an instinct that something was unusual about their child, so they had not been too surprised and the acceptance was much easier. Meanwhile, the two other fathers had been saddened and speechless. However, all the fathers admitted they had already accepted their children's condition wholeheartedly as a fact, after a short period of time. This was because they believed that their children's condition was God's gift and understood that it had happened for a reason.

***Remained calm in dealing with the situation positively***

Next, the five fathers also shared the view that although their children were challenged, they decided to deal with the whole situation positively. However, the other two fathers reported a different way of dealing with their children's condition. Nevertheless, the researchers

viewed this as a positive coping mechanism. The latter two fathers explained that they had had to take some time to be alone after learning about the diagnosis. They remained calm, but this was initially combined with sadness when they received the diagnosis. However, all the fathers were eventually able to address the whole situation regarding their children optimistically and constructively.

### ***The Fathers' Emotions in Dealing with Their Children***

#### ***Losing emotional control or becoming stressed***

All seven fathers suffered as they lost control of their temper while handling their children. This happened because, characteristically, children with autism frequently throw tantrums. The fathers could not communicate with them so it was extremely difficult to get the children to understand and do as instructed. Even basic instructions such as 'sit down', 'stand up', 'come and eat', as well as other simple instructions were not followed. As all the children in this study had speech difficulties, communication was a major problem. Therefore, the fathers felt helpless, upset and extremely stressed while managing the daily routines of their children.

#### ***Affected emotionally as a father***

Consequently, four of the fathers felt depressed and disturbed at being unable to fully function and manage their children with autism. Each expressed the feeling of being emotionally affected as a father. They felt unhappy and dissatisfied because they could not balance their time by being responsible fathers to their children with autism and to their other typical children.

### **Financial Challenges**

Two themes emerged from this issue, which were the expenses of obtaining support services and the initiative taken by fathers to address their financial challenges.

#### ***Expenses for Support Services***

All the participants faced financial burdens ensuring that their children received a service that might benefit their development. They spent considerable amounts of money on education, therapy and travelling costs.

#### ***Education***

Participants explained that they incurred additional financial burdens in providing education for their children with autism. They stressed that in Malaysia, too few mainstream schools with adequate facilities were available near their residential areas that provided inclusive education for children with autism. Therefore, the only remaining choice was to send their children to private schools for children with autism, which was either expensive or beyond their means.

### *Therapy or treatment*

Secondly, two fathers revealed they faced financial challenges in providing the therapies and treatments necessary for their children with autism. They had to spend considerable amounts of money on therapy and treatment fees.

### *Travel costs*

Participants also highlighted the high costs of travelling to attend regular therapy at the therapy centres. These costs consisted of paying for tolls and fuel.

### ***Taking the Initiative to Deal with Financial Challenges***

#### *Doing part-time work*

Participants explained that they had taken part-time jobs to supplement their income. Examples included started an online business, opening a small-scale food catering service and became a tour guide. On the other hand, four fathers stated that even though they experienced financial challenges, they managed the situation on a very restricted budget and with hardly any savings.

### **Discussion**

The aim of this research was to investigate the emotional and financial challenges experienced by fathers in handling children with autism. In relation to the emotional challenges, the fathers had accepted their children's condition and remained committed to being responsible parents. They wanted to contribute constructively by managing and raising them well. On the contrary, the results from past research reported that fathers were in denial after receiving their child's diagnosis and consequently took far longer to truly accept the facts (Hartley et al., 2010; Hoogsteen and Woodgate, 2013). However, the fathers in this study did not experience extreme emotional challenges, which may be due to their demographic background. All the fathers were from Southeast Asian cultural backgrounds; more specifically, they were Muslims, who totally submitted to the will of God to help them address the situation. Such acceptance helped them to remain mentally stronger in facing the various challenges of managing their children.

However, at times, the fathers did experience forms of psychological distress, such as anger, short tempers, impatience and exhaustion, especially when they had to deal with their child's incessant tantrums and unpredictable misbehaviour. This phenomenon was similar to situations mentioned in the findings from past research (Ahmad and Dardas, 2015; Cheuk and Lashewicz, 2015; Frye, 2015; Giallo et al., 2015; Burrell et al., 2017; Paynter et al., 2017; Hannon et al., 2019). The fathers admitted that it was emotionally challenging to deal with their child's frequent tantrums and serious misbehaviour, especially when they were working at the same time. Hence, they tended to lose their temper and explode while managing the situation. This had caused some fathers to feel dissatisfied or incapable, as they were unable to fully function and simultaneously care for their children with autism and their other normal children.

Specifically, we found that the fathers faced financial challenges related to three aspects: education, therapy or treatment and transportation costs. The fathers mentioned that they struggled to provide proper education for their children with autism due to the lack of government services and facilities for inclusive education. Significantly, it was found that only one educational institute specifically catering for children with autism was available in the country; it was located in Sentul, Kuala Lumpur. Hence, as all the fathers in the study lived in another state, they were unable to access a facility that provided the essential interventions that would have been extremely helpful for the children. This forced four fathers in this study to send their children to either private preschools run by the National Autism Society of Malaysia (NASOM) or preschools for typical children near their homes. In the long term, this had become very costly and resulted in additional financial burdens.

These findings reveal that the context of Malaysia, a developing country, is unlike the contexts of previous research findings, which were based in Western developed countries. (Cheuk and Lashewich, 2015). Secondly, the financial challenges highlighted by the participants, such as the high costs of the therapy and treatment needed by these children, were similar to the findings in past research. Speech therapy, occupational therapy and behaviour management therapy are all very costly and must be administered regularly so that the children are rehabilitated gradually. Thirdly, three fathers complained about the extra financial burdens incurred when continuously providing such treatment and therapy because the centres were extremely far away. It required a considerable amount of time, money and effort to commute between them and their homes. Significantly, this distressing scenario has not been mentioned in any past research. As a result, it must be stated that these three fathers, due to their awareness and sense of responsibility to provide for the needs of their children with autism, were forced to take the initiative to supplement their income. They did this doing part-time jobs such as starting an online business, becoming a tour guide and offering food catering services. This also reflects the fathers' sense of love and compassion for their special needs children.

Several implications stem from this study. Firstly, there is an urgent need on the part of the government and the private sector to contribute positively by providing an adequate allocation of resources and facilities for the special education and rehabilitation of children with autism, in addition to the welfare of the parents and caregivers of these children. The Ministry of Education (MOE), primarily, needs to provide more constructive and extensive programmes, while the infrastructure for inclusive education should be made feasible throughout the country. Thus, new policies for inclusive education at the primary, secondary and tertiary levels are crucially needed so that children with autism will not be ignored and neglected. Counselling and specific training programmes for the fathers to help them manage these children are also necessary. The ministry could provide more male counsellors as fathers will generally feel more comfortable sharing their anxieties and problems with another male. As a result, a father who is the main provider and caregiver will enjoy better welfare and their wellbeing will be improved in all respects: psychologically, physically, emotionally and financially.



The ministry should thus urgently accelerate the provision of more trained manpower, services and facilities, especially for the education and welfare of children with autism. They must also ensure that inclusive education is accessible for all such children. For example, more government-supported institutions like the Genius Kurnia can be established in other states, as this institution has proven beneficial and helpful for children with autism and their families in a variety of ways. More importantly, it could help fathers by reducing their financial burdens, as not all fathers can afford to send their children to privately run schools.

In terms of the special needs of children with autism, the government, through the Ministry of Health (MOH) and joint ventures with NGOs, could provide funds to improve and expand the services and facilities in terms of intervention, therapy, rehabilitation and treatment programmes. There is a dire need for this, especially in the states other than Selangor and Kuala Lumpur and in rural areas. If such provisions are made, fathers will not have to travel long distances or become financially, emotionally and physically drained. They will also not have to wait such long periods for their turn to receive intervention or therapy for their children.

### **Conclusions**

In conclusion, this phenomenological study has achieved its main objectives since it has provided a more meaningful understanding of the emotional and financial challenges experienced by fathers in handling children with autism. This research showed that fathers can face these challenges positively with good emotional and financial management. Fathers, like mothers, face difficulties in providing the best care for their children. They are superheroes who are constantly present to assist and guide their children. It is hoped that this study can provide enlightenment and guidance to other fathers in their efforts to manage and raise their children with autism. Moreover, this study can be used by the government in designing compatible support programmes in this country for children with autism and their family.

### **Recommendations**

There are several recommendations for future research. First, it is suggested that future research in this area could explore broader locations or populations by employing both quantitative and qualitative designs on a larger scale and especially involving participants from rural areas. This would enable the findings to be more comprehensive and useful for generalisation purposes. Secondly, future research should include fathers of other races and ethnicities in Malaysia, as data show that children with autism in Malaysia come from multiple races. This is because cultural and family backgrounds could greatly affect the concepts of children's upbringing, parenting and views on special needs children. Lastly, it is strongly suggested that future research investigate the challenges experienced by the fathers of teenagers with autism to ascertain if new challenges are faced by fathers in such cases. It would be interesting to explore the issue from this perspective due to the major changes that teenagers experience in their lives during puberty.

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