



Experiences And Difficulties Of Parents In Caring Their Children With Autism Living In Malaysia

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ABSTRACT

Bringing up a child with autism is very challenging for parents. They face a lot of physical, emotional and financial challenge in their life. Different degrees of behavioral difficulties often accompanied with social skills impairment. The aim of this study was to find out the living experiences of caregivers with autistic children living in Malaysia. Qualitative study with purposive sampling method was used. This study used semi-structured, in-depth interview for data collection. There were 10 participants in this research. The thematic analysis revealed four themes which are challenges in daily lives which include problem in work flexibility, difficulties to go out and educating child at home. The other themes were emotional challenges, financial challenges and physical challenges. Majority of the parents interviewed in this study face challenge in their daily life. They also expressed that they experienced emotional challenge since the diagnosis of their children. The majority of the parents also said that they do not experience physical effect such as headache, chest pain, high blood pressure, diabetic, cholesterol and frequent get flu but they had mentioned they felt fatigue. Fortunately, in this study had found that 7 out of 10 respondents do not have financial problem.

Keywords: Autism; Living experiences; Financial challenges; Emotional challenges; Physical challenges

INTRODUCTION

Autism Spectrum Disorder (ASD) can be defined as a neurodevelopment disorder that affects an individual's ability to interact and communicate with others (American Psychiatric Association, 2012). Besides that, different degrees of behavioral difficulties often accompanied with social skills impairment (American Psychiatric Association, 2012). Nowadays, many Malaysian children are being diagnosed with autism spectrum disorder (ASD) each year, this caused a demand for places in autism focused pre-schools or early intervention centers (Dina Murad, 2019). There is no official registry for the number of children diagnosed with autism in Malaysia. However, World Health Organization (WHO) estimates that 1 in 160 children have ASD and its prevalence appears to be increasing globally over the 50 years. There are many possible explanations for this spike including expansion of diagnostic criteria, better diagnostic tools and improved reporting (WHO, 2018).

Bringing up a child with autism is very challenging for parents. Families with autistic children generally earn 28 percent less than families with non-autistic children because of loss of one parent's income. Consistent with similar studies, physical fatigue is found to be a very critical issue, which affects the daily occupational

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functions of parents and the ability to take care of their children. Most of the care giver will feel tired and frequent get sick due to caring for autistic child. Caregiver burden is a combination of psychological, physical, emotional, economic, and social stress. The main objective of this study was to find out the experiences of caregivers living with a child with autism in terms of their financial, emotional and physical outcome.

RESEARCH METHODOLOGY

Sampling method

Respondents were obtained through convenience, snowball sampling by contacting the local Community-based rehabilitation (CBR) and National Autism Society of Malaysia (NASOM) in Penang. Convenience sampling is a method of collecting samples that are conveniently located around and near to the location of the researcher (Study, E., 2021).

This study being a qualitative naturalistic inquiry designed to obtain insights into the life experiences of caregivers of child with autism, theoretically requires a minimum number of 15 until saturation of data (Saunders, B., 2018). As this study aims to find out information about the daily lives of a population, in this case that caregiver with autism child living and working in the Penang area, it was decided that a significant parents of ASD child should be recruited in order to obtain a wider spectrum of perspectives.

Inclusion and exclusion criteria

Inclusion criteria

- Parents of the child between 2 to 7 years old with ASD only
- Literate in English and Bahasa Malaysia
- Parents who are Malaysian and lived in Penang.

Exclusion criteria

- Parents of the child aged less than 2-year-old and more than 7 years with multi diagnosis
- Parents with mental health problem
- Parents who are foreigner

Data collection

This study used semi- structured, in-depth interview for data collection. A semi-structured interview is a meeting with respondent which interviewer does not strictly follow a formal list of questions. Instead, interviewer will ask more open-end questions and allow discussions with respondents, rather than a straight forward question and answer format (Interview, S., 2021).

Data analysis

Data was evaluated after all of the interviews were completed. The interview questions inquired about challenges, experience and needs to examine the main cause of challenge in life for the participants.

Firstly, researcher listened to the interview audio recording and then the audio recording results of the interviews will then be transferred onto the researcher's computer and digitally transcribed all of the responses verbatim into text in Microsoft Word files. After that, researcher reviewed each transcript and identified the themes as well as any differences between each of the participant. Researcher was focused on the major ideas in each transcript and sorted out the main factor of challenge in life for each of parents. Researcher obtained the major ideas from respondents' responses for each interview question. Researcher looked for key words in each of question that represent a main idea. Main problem as identified by response themes or patterns from each respondent were then listed, investigated, identified, and compared by generating a tentative list with similarities and differences among participants. Findings in this generative list were obtained by interview question to support the specificity. Researcher included immediate quotes from respondents' answers to support particular findings from the analysis.

Ethical consideration

Ethical approval was obtained by the Perdana University Institutional Review Board (IRB). This research did not involve a vulnerable population and has minimal risk to the subjects. Informed consent was acquired for all participants. Information explaining the purpose of this research project, as well as contact information of investigator, was provided to all subjects. Any questions and concerns of the respondents were addressed by the researcher.

RESULTS

Ten respondents involve in this study were parents who have ASD children living in Penang Malaysia.

Table 1: Demographic profile of respondents

Respondent	Age	Gender	Level of education	Occupation
A	47	Female	SPM	Hawker
B	36	Female	SPM	Clerk
C	41	Female	SPM	Housewife
D	35	Male	Diploma	Marketing
E	44	Female	SPM	Housewife
F	35	Male	Degree	Salesman
G	30	Female	Diploma	Accountant
H	35	Male	PMR	Postman
I	28	Male	SPM	Marketing
J	32	Male	Diploma	Salesman

Theme 1: Challenges in daily lives problems in work flexibility.

These participants do not have to choose between work and children's access to the services they need. For those with disabled children, some policies should be formulated to give caregivers a certain degree of flexibility in working hours. Unless there were family members with special needs, caregivers will be able to use unpaid days. Although allowing caregivers to get unpaid leave can reduce the pressure they face at work risks, it will increase their burden because they only need to not pay on that day. The formulation of policies such as this will mean that people have realized that the caregivers of children with disabilities do bear more responsibility to ensure the health of their children (Blair et al., 2011). For those respondents who have flexibility in their work arrangements, they realize that they were lucky, and did not have any problem for them.

Difficulties to go out

Going out to different places such as supermarkets, parks and other people's houses often caused difficulties for the parents with ASD child. Many children usually have obvious signs of autism. If they behave abnormally or lose their temper when they go out, people who don't know them may think they were not behaving appropriately or spoiled. Besides that, it was also difficult for the family with ASD child to go out and eat in a restaurant or visit to relatives' houses. When children show unusual behaviors in public, parents will feel difficult and embarrassed. Some parents find it difficult to cope with how others react to their children. They often feel hurt by the reactions of others.

Educating child at home

In fact, that ASD was not something a person simply "grows out of," they need a lot of treatments that can help them acquire new skills and overcome different stages of developmental challenges. In this study, it was found that 4 out of 10 respondents spending more time to guide their child to improve their child. They also follow the advice and guideline given by the therapist and doctors. They will find out what therapists were doing and follow their techniques at home.

For the other respondents in this study, they had mention that mostly they will spend their time and teach their child by playing. Children with ASD were still very young. They need more enjoy in life than therapy and education for both children with ASD and their parents. Arrange playtime when your child was most alert and awake. Find out the ways to play together by thinking about what were the things that can make children smile, laugh, and stand out. Usually, child was likely to enjoy these activities if we make this therapeutic or educational as a play.

Theme 2: Emotional challenges

In this study, we found that most of the respondents were feeling sad, worried and stress. Only 2 respondent they deny they have emotional effect and still able to cope. Parent stress due to child with autism has difficulties to understand the meanings through verbal or non-verbal language, for example, language, body language and facial expressions. This can make the conversation and communication difficult because the child does not understand the need to reply in a conversation; therefore, it was not easy to make another person's intentions. As a result, the relationship between the parents and child become very one-sided. They will end up with they do not understand to each other.

Some parents will feel worried and some parent will feel sad when they compared their child with other child and also, they noted that their child had delay and absence of language development. Stigma and bad word were one of the most difficult aspects of public encounters experienced by families with an ASD child. They often find that public reaction to them was rigid and negative. As a result, even the parent will feel hurt but they still pretend to be okay.

Theme 3: Financial challenges

Fortunately, in this study, we found that 7 out of 10 respondents do not have financial problem, for example Respondent A said: “Kewangan tak ada masalah (so far still can afford)”. Some of the respondents claim that both of the parents were working and they were supportive to each other. For example, respondent D said: “*Kewangan.... sebelum ni ada la. sekarang ni dah ok... jadi sekarang dah jadi normal la..biasa la...kalau dia cuti dia bawa..saya cuti saya bawa...ah..sudah biasa..ada buat jadual...*” (Financial.... there was before this. now it's ok... so now it's normal... it's normal... if he's on holiday he brings it.. I'm on holiday I bring it... ah.. it's normal.. there's a schedule...). One of the respondents claims that now he was doing part time job to increase his income. Respondent H said: “*Macam kewangan sekarang saya pun krerja pagi malam, macam malam saya buat part time security...pagi saya buat hantar-hantar surat macam tu lah..post sender lah..*” (As far as finances are concerned, I also work in the mornings and nights, as in the evenings I do part time security... in the mornings I send letters like that.. post sender..)

If time was money, then sacrificing the time was probably the most expensive thing for these families must pay for. Parents must choose to work fewer hours, reject overtime or even stop working to take care of their autistic child. Parents with autistic children have less time to spend together and support to each other than their child's needs. The financial losses here were most difficult to quantify but there was certainly a truth. Some of the parents will lose out on opportunities for promotions or second jobs. They were desperately needed free time. In this study it was found out there were 3 out of 10 respondents had facing some impact on their finance.

Theme 4: Physical Challenges

In this study all of the respondents claim that they do not have any physical illness problem when taking care to the child with autistic. But only one thing most of them had mentioned, which was fatigue. Fatigue was also known as reduced energy, tiredness, physical exhaustion, or lack of motivation (O'Connell, K., 2012). Fatigue was always related to a negative experience. Fatigue and then burnout can happen to anybody. Parents with autistic child will get fatigue and burnout more likely, due to the pressures in taking care of their autistic child. Most parents of newborn children will also experience some level of fatigue; undeniable parents who have children with autism spectrum disorder will give a deep sense of exhaustion.

DISCUSSION

Analysis of the interview supports the findings of the literature on caring for children with autism. The parents interviewed in this study experienced emotional challenges at every point in the caring of their children. They have to take care of their child's daily activities that are not only included activities such as bathing and feeding, but also included most of the medical and educational decision making. They have to deal with the child's appointment system, financial hardships from increased expenses and reduced work hours. Parents in this study were responsible for every aspect of care for their autistic children and as a result they always needed to consider their children's needs. This division of labor was reliable whether or not both parents were employed. Within the family unit, both of the parents will decide that one of them needs to quit their job or decrease their work hours in order to take care for the child with autism fully and this led to the reduced financial income. This finding agrees with previous research that parents of children with autism are more likely reduce their income because they leave the paid labor force or reduce their work hours (Ryan J, 2012).

In this study some of the parents will try to get information, advice and guideline given by the therapist and doctors and follow their techniques at home. Even though they have support from professionals; most of the parents are still experiencing fatigue in caring their autistic child. In previous study, it was found that fatigue is a very common issue that always happens on parents with autistic child (Bennie, M, 2021). It can affect parent's ability to take care for their children. It is important for parents to have followed up with doctor and get some guidance and recommended treatment plan for them. If left untreated, fatigue can affect their physical and emotional well-being.

Parenting stress for caring the autistic children was different with the stress of caregivers of typical children. There are many factors that increase caregivers stress such as behavioral problems (aggression and tantrums), cognitive impairments, language deficits, learning disabilities, sexual expression, mood disturbances, functional dependence (lack of self-care abilities, toileting difficulties and other in daily living), noncompliance, hyperactivity, social difficulties, imposed limits on family opportunities, need for care across the lifespan and a high likelihood in unable to go for work when they grow up. It was found that the parents with the most stress are those children with ASD having significant aggression, hyperactive, tantrums, incompilance or unpredictable behavior.

Study also found out that most of the parents claimed they were having difficulty to go out for shopping or visiting relative's houses. Parents can find it difficult and embarrassing when their child demonstrates inappropriate behaviors in public. It is already challenging to care for a meltdown child, they also have to deal

with everyone's judgment too (Matthew, B., 2021). Usually, children with ASD have sensory processing issue. They found difficulty to go to different places because they were unable to cope with environmental changes, such as different lights, loud noises, or too many people around. Therefore, many ASD children found shopping difficulty and would go into meltdown. Some of the parents have difficulties in going out and were worried about ASD children safety. Most of the ASD children had no sense of road safety and they would run off and play with stranger. In this study, parents also mention about the difficulties in going to relative house or other people's houses because their children might simply take something and break something or are disruptive. It was not just the problems that could happen during an outing, but parents also worry about an unexpected problem arising suddenly. Going out has brought various problems to parents. These problems are related to the non-visibility of the children's autism, the difficulty of the autistic children had sensory issues and a need for order in their lives, and also the attitudes of others. The parents must find the strategies for going out to overcome these difficulties.

Focus of this study was on parent's lived experience in caring children with autism. Research has found that parents caring for disabled children experience emotional problem, physical strain, and financial hardship (AARP, 2020). Effect of emotional level, physical stress and financial hardship of the caregiver is dependent on the degree of burden in taking care children with autistic and severity level of the condition (AARP, N. A. for C, 2020). Nevertheless, when comparing between taking care of children with autism with other disabilities, caregivers of children with autism have been found to have higher levels of stress, fatigue and financial problem (Goldschlag, N et al, 2019) due to condition of the child and their medical and education expenses.

Besides getting information and advices from professionals, it needs to be remembered that other parents of autistic children can be a good source for tips and suggestions in handling a child with autism (Society, N. A., 2018). So, it is suggested for parents to join a local support group where all the parents can share their experiences and support each other. These groups usually offered a place for parents to share their experiences, to get information and advice and to make friends. In some cases, campaign for better services and provision for their children will be organized. Mostly the life parents seem to be very different from the other families without autistic or disabled children. Therefore, it is possible for them to feel that there is no way for them to ask for or expect other people to understand their experiences. However, things can be easier once they have a support group. These are the benefits and importance of being able to join a support group for parents of autism children.

CONCLUSION

Larger findings of the study came in the form of identifying the challenges in their life. Participants had highlighted few issues that cause them the most challenges as caregivers. These were work flexibility, difficulties to go out, educate children at home, financial challenges, emotional challenges and physical challenges. Seven out of 10 respondents face difficulty in work flexibility. They feel challenge and some need to stop their job or change their job. Almost half of the respondents claim they had difficulty to go out by bringing their autistic children due to their unusual behavior and also stigma from public. 4 out of 10 respondents feel challenging in educating their autistic child but they still had follow therapist and doctor advice to educate their children. The other respondents they feel play is more suitable for their children. Majority of the parents interviewed in this study expressed that they experienced emotional challenge since the diagnosis of their children. The majority of the parents also said that they do not experience physical effect such as headache, chest pain, high blood pressure, diabetic, cholesterol and frequent get flu. But only one thing most of them had mentioned, which was fatigue. Fortunately, in this study had found that 7 out of 10 respondents do not have financial problem. All of these issues were challenging, it is suggested that the parents should join support group so that they would not feel lonely and thought that they are the only one have to face this problem. When it comes in supporting caregivers, support is essential because caregiver's stress will not only affect the individuals but also the children.

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