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# Relationship Between Knowledge and The Level of Stress among Caregivers with Autism Spectrum Disorder (ASD) Children

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**Abstract**

This study analyzes the relationship between the knowledge of caregivers of Autism Spectrum Disorder (ASD) children and the stress they experienced in caring for and educating these ASD children. In general, ASD is a brain disorder that causes neurological developmental disorders in a person in the long term. Some caregivers of these ASD children experience stress that can affect the caregiver's mental health. Thus, a quantitative study was conducted on 130 caregivers of ASD children. Data were analyzed using descriptive analysis and Pearson Correlation. The study's results found a non-significant relationship between knowledge and stress levels among caregivers of ASD children. Suggestions for improvement were also given to caregivers of ASD children, non-governmental organizations (NGOs), communication media, and social workers to increase caregivers' awareness of the importance of having knowledge about ASD and mental health care to alleviate stress. It is hoped that through this study, the community understands, realizes, and help change any negative perception of ASD children and their families.

**Keywords**: Knowledge, Caregivers, Stress, Autism

## Introduction

Every child born into the world is special and unique in their own way. However, some children are born with certain disabilities in some aspects. Among the categories of these disabilities are children with autism. Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder that affects the brain's development and the ability of the individual to communicate, socially interact, and learn like other ordinary individuals growing up (Hodges et al., 2020). Section 2 of Persons with Disabilities Act 2008 defines persons with disabilities (PWD) as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective

participation in society." Among those who can be categorized as PWDs are children with ASD.

The prevalence of children diagnosed with autism spectrum disorder worldwide is 1/100 children (Zeidan et al., 2022). Meanwhile, boys are four times more likely to be diagnosed with autism than girls. In addition, according to statistics released by the National Association of Autism Malaysia (NASOM)(2022), in 2016, one in every 150 children born worldwide has autism symptoms. Subsequently, it is estimated that 47,000 children in Malaysia currently have autism, with the average age ranging from six months to the late 20s. NASOM also estimates that there are about 9,000 children in Malaysia are born with autism every year. Therefore, this figure clearly shows that many children have autism worldwide, including in Malaysia. Despite the prevalence of children with autism, there is currently no single treatment capable of curing autism (DeFilippis & Wagner, 2016). This situation presents many challenges and stress for parents, especially those with little knowledge about autism. These parents are often reported to have higher stress levels than parents of normal children (Lee, 2017).

The level of knowledge about autism is divided into three levels: low, medium, and high. In Malaysia, there are several issues and cases related to autism within the Malaysian community, often involving misunderstandings, abuse, and so on. For example, a recent abuse case involving an autistic child and a caregiver in a childcare center. The caregiver had abused the child, causing serious injuries to the child's shoulders and eyes. This incident may be due to the caregiver who did not have a high level of knowledge of autism and therefore did not know how to care for an autistic child properly. There was also a case in 2018 involving an autistic man who was charged with molesting a woman. The public criticized the victim's family for filing a police report even though the autistic man's family explained that the accused had autism. People also condemned the police for arresting the accused despite knowing about his condition. The accused was released after the court rejected a remand order for his arrest. This situation clearly shows that many Malaysians still have a limited understanding and knowledge of autism or have no knowledge of it (Low et al., 2021).

As such, this situation has put pressure on parents, especially the caregivers of autistic children, in raising the children. This pressure occurs not only when dealing with the temperaments of an autistic child but also when engaging with a community that lacks knowledge about autism. One of the most common reactions the caregivers get from the public is people boycotting the child and having negative perceptions of the child. In conclusion, every child's caregiver has different knowledge levels of autism, and the disparity can cause them to be under immense pressure. Therefore, this study aims to identify the ASD children caregivers' knowledge and stress levels in Selangor area specifically at one of the NGO of Autism.

## Literature Review

### *Knowledge*

Knowledge results from curiosity through a sensory process, primarily via the eyes and ears, towards a particular object and is an essential domain in forming open behavior (Donsu et al., 2017). It is also the result of a person's observation or knowledge of an object through the senses, for example, through vision, hearing, touch, and smell. However, a person can gain most knowledge through sight and hearing (Notoatmodjo, 2014). Knowledge can also be influenced by factors like formal education, for example, during the education process in schools, universities, and others. People commonly think that the higher the level of

education, the more knowledge is gained. However, lowly-educated people do not necessarily have a low level of knowledge. This assumption is untrue because increasing one's knowledge is not always done through formal education but can also be done through informal education. Factors contributing to the negative attitude and perception toward ASD children are mainly due to the public's lack of knowledge and understanding of the needs and problems of ASD children. According to Shamsudin and Abd Rahman (2017), the lack of knowledge and awareness of ASD has led to society's negative perception of ASD children, which in turn has a negative impact on parents with ASD children.

***Level of Stress***

Stress is identified as the cause of almost all problems and psychological disorders. For example, a person constantly suffering from stress will suffer depression, sadness and anxiety. These can occur because of multiple factor including quality of life and health issues (Mofatteh, 2021). Regardless of the form of stress that human beings are experiencing, stress needs to be overcome in any way possible. If stress is left untreated, it will cause harm to health and affect the quality of daily life. Suhaimi and Amelia (2018) stated that the community had labelled ASD despicable. Families with ASD children often have difficulty going out in public, where they repeatedly face social stigma from the local communities. This stigma, conveyed via verbal or non-verbal behaviour, is a critical factor in the fall of self-motivation among parents with ASD -problematic children.

The parenting phase is a phase that is full of stress. However, the causes of stress for parents of normal children and parents of ASD children are different because the pressure caused by having normal children is primarily due to the misbehaviour or stubbornness of the child. On the other hand, parents with ASD children have the additional pressure of dealing with stigma from the public on top of the pressures of handling ASD children, especially those with temper tantrums. Previous research has found that children with developmental imbalances contributed to increased parental stress levels, whereby parents with autistic children recorded higher stress levels than parents with other developmental imbalances (Lee & Abd. Rahman, 2017).

## Methodology

This study uses a quantitative approach conducted through a survey method as non-experimental research using the questionnaire form given to the study subject (Piaw, 2011). It is to ascertain the relationship between knowledge and the stress of caregivers of ASD children. This study was conducted in one of the NGO in Selangor. The total sample was 130 people comprising the caregivers of ASD children from the NGO.

***Instrument***

The study uses the questionnaire form as an instrument and includes three sections: Part A, Part B, and Part C. Detailed information on the research instrument is as follows:

**Part A: Profile background**

The information collected in this section is crucial as it is considered proof of the background of the sample that contributes to the research. The required information is as follows:

1. Gender
2. Age
3. Religion

4. Ethnicity
4. Level of education
5. Family income

**Part B: Knowledge**

This section uses the Autism Knowledge Questionnaire (AKQ) by (Stuart et al., 2008). This which has been translated into Malay. This section contains 20 questions consisting of three knowledge fractions of autism: ethology, diagnosis, and characteristics of specific ASD disorders.

**Part C: Stress level**

The test tool used to measure stress in this study is the Perceived Stress Scale PSS-10 (Cohen et al., 1983). This tool calculates the extent to which a situation in one's life is considered stressful. This section consists of 10 questions on how often the respondents felt a certain way and uses a five-point scale from 'never' to 'very often.' The answers are then scored as follows:

Never = 0
Almost never = 1
Sometimes = 2
Fairly often = 3
Very often = 4

***Instrument reliability***

The validity and Reliability of an instrument are essential to ensure that the findings obtained are reliable and unquestionable (Kerlinger and Lee, 2001). In Piaw (2011), a reliability value of 0.65 and above is the best and is very suitable for use as an instrument. If the reliability value is lower than 0.65, the research instrument is not relevant for use in the study as the data obtained are not robust. This study has set 130 samples to answer a questionnaire. The respondents consist of a group of caregivers for autistic children.

Table 1
*The reliability value of each variable instrument*

| No | Variable Scale | Cronbach Alpha Value |
|---|---|---|
| **1** | *Autisme Knowledge Questionnaire, AKQ* | 0.062 |
| **2** | *Perceived Stress Scale PSS-10* | 0.083 |

***Data Analysis***

Data analysis is an essential factor in a study. The data analysis is related to the objectives and hypotheses of the study. The data collected is analyzed by the researcher using the help of the Statistical Packages for Social Science (SPSS) 20 IBM application.

**Result**

***Demography***

A total of 130 respondents were involved in this study. The respondents are the caregivers of Autism Spectrum Disorder (ASD) children, mostly aged between 21 to 60. Table 3 shows that the number of respondents aged 21 to 30 is 18 or 13.8% of respondents. Subsequently, 87 or

66.9% of the respondents are aged between 31 to 40. Meanwhile, 22 respondents, or 16.9%, are between the ages of 41 and 50, and 2 respondents, or 1.5%, are between 51 and 60. Finally, one person, or 0.8%, a 16-year-old caregiver, is also involved in answering this survey. The percentage of ethnic groups involved in the study showed that the highest is Malay, with 117 respondents (90%). Nine respondents (6.9%) are from other ethnic groups, while two respondents (1.5%) are Chinese, and the last two respondents (1.5%) are Indian. Regarding the religious status of the respondents, the highest percentage is Muslim, with 93.1%, while Hindus, Buddhists, and Christians make up 1.5%, 0.8%, and 4.6%, respectively. An analysis of the education level found that 1.5% of respondents are UPSR level, 14.6% are PMR/ PT3 level, and 30.8% are SPM level. A total of 43.8% of respondents are STPM education/ Certificate of Skills/ Diploma or equivalent level, while 8.5% have a bachelor's degree. Lastly, 0.8% of respondents have a masters and doctorate. The overall mean of the education level is 4.45, while the standard deviation is 0.924. Meanwhile, the family income analysis shows that the respondents in the B40 category make up 54.6%, while the total samples in M40 and T20 categories are 32.3%and 13.1%, respectively.

***Knowledge***

The results show that most caregivers always respond to each item asked. This score indicates that the caregivers know about their child's condition and what to do.

Table 4
*Knowledge Score*

| No. | Question | Percentage (%) | | | |
|---|---|---|---|---|---|
| | | **Often** | **Rarely** | **Never** | **Do Not Know** |
| 1. | ASD children experience verbal/speech delays | 88.5 | 10 | 0 | 1.5 |
| 2. | ASD children have difficulty communicating | 85.4 | 13.1 | 0 | 1.5 |
| 3. | ASD children experience difficulty with social interactions | 83.1 | 14.6 | 0 | 2.3 |
| 4. | ASD children avoid eye contact | 80.8 | 17.7 | 0 | 1.5 |
| 5. | ASD children have intellectual disabilities | 40.0 | 49.2 | 4.6 | 6.2 |
| 6. | ASD children show restricted and repetitive behavior, interest, or activity | 80.8 | 13.8 | 2.3 | 3.1 |
| 7. | ASD children have behavioral problems (throwing objects, acting aggressively towards others, screaming) | 47.7 | 43.1 | 6.2 | 3.1 |
| 8. | ASD children show hyper or hyporeactivity towards | 81.5 | 14.6 | 0 | 3.8 |

| | | | | | |
|---|---|---|---|---|---|
| | sensory inputs or show extraordinary interest in environmental sensory inputs | | | | |
| 9. | ASD children have extraordinary talents | 62.3 | 31.5 | 0.8 | 5.4 |
| 10. | ASD does not affect verbal understanding | 23.1 | 67.7 | 9.2 | 0.553 |
| 11. | ASD is more prevalent among girls than boys | 10.0 | 63.1 | 26.9 | 0.586 |
| 12. | Symptoms of ASD are very different from one person to another | 87.7 | 9.2 | 9.2 | 0.440 |
| 13. | Difficulty in retaining attention is often found in ASD children | 97.7 | 0.8 | 1.5 | 0.261 |
| 14. | ASD children are generally good at expressing their intention, wants, and trust to other people | 60.0 | 13.1 | 26.9 | 0.875 |
| 15. | ASD children are usually more interested in details and specifics | 73.8 | 7.7 | 18.5 | 0.788 |
| 16. | ASD children usually adapt to change easily | 9.2 | 85.4 | 5.4 | 0.382 |

Table 5
*Knowledge of the diagnosis*

| **No.** | **Question** | **Percentage (%)** | | | |
|---|---|---|---|---|---|
| | | **Biological** | **Genetic** | **Clinical** | **Do Not Know** |
| 17. | How is ASD diagnosed? | 0 | 2.3 | 93.8 | 3.8 |

Table 5 shows the highest percentage, 93.8%, or 122 of the 130 respondents, answered that ASD is clinically diagnosed. The results of this particular question indicate that caregivers of ASD children know how ASD is diagnosed.

Table 6
*Knowledge of the current number of children with ASD*

| No. | Question | Percentage (%) | | | |
|---|---|---|---|---|---|
| | | 1 in 100 | 1 in 1,500 | 1 in 15,000 | Do Not Know |
| 18. | Current number of children with ASD | 33.8 | 19.2 | 2.3 | 44.6 |

Table 6 shows that 44.6% or 58 of the 130 respondents do not know the statistics and ratios for children with ASD. However, 33.8% of respondents chose the correct answer, 1 in 100 children with ASD. Therefore, it is clear that there are still many ASD child caregivers who do not know the ratio of current children with ASD.

Table 7
*Knowledge of Types of Disorders*

| No. | Question |
|---|---|
| 19. | Compared to others in the population, individuals with ASD may experience the following: (Mark (/) on the box that best suits your answer) |

| | Disorder Type | Percentage (%) | | | Standard Deviation |
|---|---|---|---|---|---|
| | | More Frequent | Less Frequent | Frequent | |
| a) | Depression | 6.9 | 47.7 | 45.4 | 0.615 |
| b) | Anxiety | 21.5 | 56.2 | 22.3 | 0.665 |
| c) | Obsessive-Compulsive Disorder | 25.4 | 50.8 | 50.8 | 0.704 |
| d) | Phobia | 18.5 | 54.6 | 26.9 | 0.671 |
| e) | Eating Disorder | 26.9 | 54.6 | 18.5 | 0.671 |

Table 7 shows the highest percentage, 26.9% of respondents experience eating disorder more frequent, 50.8% of respondents experience obsessive-compulsive disorder frequent and 56.2% of respondents, answered less frequent for anxiety.

Table 8
*Behavioral Knowledge*

| No. | Question |
|---|---|
| 20. | A behavior is considered challenging when (several possibilities of answers) |

| Answer | Percentage (%) |
|---|---|
| It poses a danger to the ASD individual | 11.5 |
| It poses a danger to others | 11.5 |
| The situation will likely become more serious without intervention | 1.5 |
| It makes it difficult for social integration | 7.7 |
| It disrupts learning | 6.2 |
| None of the above | 1.5 |
| All of the above | 54.6 |
| I do not know | 5.4 |

Based on the table above, the highest percentage is 54.6%, with 71 respondents selecting all of the above as challenging behavior. The second highest percentage is 11.5%, each of which 15 respondents chose the answer that it would be dangerous to the ASD individual and a danger to others.

***Stress***

Table 9 shows the analysis results on the pressure level of caregivers of ASD children. The results show that 2.3% of respondents have low-stress levels, 83.1% have moderate stress, and 14.6% have a high-stress level. The analysis indicates that most caregivers are under stress at a moderate level.

Table 9
*Stress Level*

| Stress | Percentage (%) |
|---|---|
| Low | 2.3 |
| Moderate | 83.1 |
| High | 14.6 |
| Total | 100 |

*The relationship between knowledge and the caregivers' level of stress*

The results show a non-significant relationship between knowledge and stress levels. The variables recorded -1.92 on the results of the data analyzed. Therefore, the hypothesis is that there is a significant relationship between knowledge and stress levels among caregivers of ASD children is not accepted.

Table 10
*Relationship Score*

| Variable | Stress Level |
|---|---|
| | r |
| Knowledge of Autism Spectrum Disorder | -1.92 |

p>0.05

**Discussion**

Based on the research conducted, there is no significant relationship between knowledge and stress levels among the caregivers of ASD children. This study shows that most ASD children caregivers know about autism, while their stress levels are moderate. Although the stress level is moderate, this does not mean that autistic children's caregivers do not feel depressed when managing and raising children with autism. According to previous studies, when talking about ASD, the family stress level is high (Zuckerman, 2018). In the Lee and Abd. Rahman (2017) study, 30 parents with ASD children from the National University of Malaysia Medical Center, Tangkak Hospital, and Autism Center (NASOM) in Muar and Segamat were given the third issue of the Parenting Stress Index. Through this survey, the level of stress obtained showed a far higher percentage than 36 parents to children with Typical Development (TD) in the control group. They found that parents with ASD children showed higher stress levels ($p < 0.001$) than parents with TD children. Manan et al (2018) found that 78 parents living in the Klang Valley have two to eight-year-old ASD children with higher parenting stress levels and tend to have a higher level of depression than parents with low parenting stress.

**Conclusion**

The results of this study raise questions about the knowledge and stress level of caregivers of ASD children around Selangor. It can increase the caregiver's knowledge of the right way to identify the knowledge and stress levels that ASD caregivers face. In addition, it can help the caregivers choose efficiently and the right course of action that is appropriate to the level of stress they face so that they can resolve problems effectively. Caregivers can also understand the relationship between their knowledge and their stress level. Additionally, the caregiver's exposure to ASD-related knowledge and their linkages to stress levels is also necessary for assisting them in navigating their daily lives as caregivers of unique children with ASD. Through this study, the researcher has identified that most caregivers of ASD children experience moderate stress levels. This situation improves if they are equipped with adequate knowledge and have access to a proper support system. Suppose the initial steps to alleviate the problem are not taken. In that case, more unfortunate incidences related to interactions with ASD individuals, their caregivers, and the public will likely happen. These situations will cause further misunderstandings about ASD and drive the caregivers' stress levels even higher. A high-stress level can cause unpleasant repercussions like the deterioration of mental and physical health, depression, and even suicide.

In this case, ASD-related non-governmental organizations (NGOs) play a huge and vital role that the government cannot fulfill. They fight for the ASD community and public interest by raising awareness about ASD. NGOs also provide a much-needed, supportive environment where they often serve as a major reference point and voice for ASD children and their caregivers. NGOs like NASOM, for example, offer lifelong services for autistic individuals by providing ASD individuals with various services and programs with the ultimate goal of skills acquisition and behavioral change. NASOM offers essential services like assessment, diagnosis, and even therapy sessions. In line with these vital roles, the NGOs need to ensure they work hand-in-hand with the caregivers to further disseminate as much relevant ASD-related information as possible so the public will have more empathy and can understand the challenges faced by the ASD community. There have been many countries that have employed unusual tactics to spread ASD awareness. A great example is where NGOs, ASD children, and caregivers in the United States use social media applications like Tik Tok or Facebook to reach a larger audience. This step not only breaks existing stigmas but helps with the caregivers' stress levels and can enhance the well-being and harmony of the whole family.

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