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## Awareness of Autism among Parents

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### Abstract

Autism is a complex neurobehavioral condition that includes impairments in social interaction, developmental language and communication skills combined with rigid and repetitive behaviours. The aims of this study are to identify the awareness level of Autism Spectrum Disorder (ASD) among parents that have a child with or without autism, and to investigate the relationship between the determinants (knowledge, role of government and community living) with the awareness of autism among parents by using ordinal regression analysis. The study reveals that a majority of parents have a medium level of awareness about autism. While the rest, have an equal percentage which is 20% respectively for high and low level of awareness about autism. From this study, it can be concluded that there is a relationship between knowledge and government role with the level of awareness of autism among parents.

**Keywords:** Autism, parents' awareness, ordinal regression analysis

### 1. Introduction

Each birth is a miracle. Babies who are born healthy and normal can bring joyous and happiness to the parents and the rest of the family. However, birth have unexpected risks and processes. Some baby can be exposed to autism. Autism is a complex neurobehavioral condition that includes impairments in social interaction, developmental language and communication skills combined with rigid, repetitive behaviours. Because of the range of symptoms, this condition is now called Autism Spectrum Disorder (ASD). It covers a large spectrum of symptoms, skills and levels of impairment. Children with autism have trouble

communicating. They have trouble understanding what other people think and feel. This makes it very hard for them to express themselves either with words or through gestures, facial expressions and touch (Smitha Bhandari, 2017).

A child with ASD who is very sensitive, and as such may be greatly troubled by sounds, touches, smells or sights that seem normal to others. Children who are autistic may have repetitive, stereotyped body movements such as rocking, pacing and hand flapping. They may have unusual responses to people, attachments to objects, resistance to change in their routines, or aggressive or self-injurious behaviours. At times they may seem not to notice people, objects or activities in their surroundings. Some children with autism may also develop seizures. And in some cases, those seizures may not occur until adolescence. People with autism show uneven skill development. They may have problems in certain areas, especially the ability to communicate and relate to others. However, they may have unusual developed skills in other areas such as drawing, creating music, solving math problems or memorizing facts.

The case of autism in Malaysia is one of the fastest growing disorders. Autism is a development brain disorder found in children and it is still not getting appropriate attention. There are still a lot of gaps in the minds of Malaysians towards understanding autism. At present, the public and parents still have limited information, knowledge and experience to deal with people who have autism. Some parents out there lack information or are not aware whether they have children with autism or not. However, detecting autism features can be difficult as most non-autistic children sometimes exhibit the same behaviours. Therefore, to detect it, parents need to have an extra effort to understand autism. This it is not only to parents but also to everyone else too.

Several researches have been done over the past few decades by applying various techniques. However, there was not much research being done in analysing the awareness on autism among parents in Malaysia. Therefore, this study is carried out to explore the level of awareness of autism among parents as well as to uncover the knowledge of autism, role of government and community living which are believed to have an effect to the awareness of autism among parents.

## 2. Literature Review

All the variables comprise both dependent and independent variables. These variables were studied from the previous research to support and give information towards the researchers' current study. Besides that, these variables were also studied whether it will affect the awareness of autism before the researchers conduct the real study.

According to Shamsudin and Abdul Rahman (2014), it was found that about 70% of people are familiar with the word of autism but not all can describe the word autism, the physical appearance of autistic children, the characteristics of autistic children and others, they only know the word autism. The misconception is that some of them think that autistic people are similar to hyperactive people. It shows that the citizens are still not aware of autism, and the misconception of autism makes a huge problem in our daily life. Hence, there are three determinants to assess the level of autism awareness among parents which are knowledge, role of government and community living.

The first determinant is knowledge. Knowledge is a fact, information and the theoretical or practical understanding of a subject. It also means knowing about or being familiar with something; in relation to this study, it is about autism. Some researchers (George & Sakeer,

2015) have done a program to know the level of awareness of autism among parents. They give the questionnaire to the parents before and after the program to look at the impact of the program to the parents. Before the program was done, only 19% of them have heard of autism but after the program 99% of them understand and are aware of it. After the program, about 100% of parents agree with the statement that autism is associated with mental retardation. 99% of parents also agree that autism is a genetic disorder and a neurodevelopmental disorder (George & Sakeer, 2015). This shows that there is a relationship between the knowledge of autism and the awareness on autism.

A government is the political direction and control exercised over the actions of the members, citizens, or inhabitants of communities, societies and states. Local authority should provide proper facilities for children with autism. For example, they should have more public schools that take autistic students, as well as schools that specialize in care of autism students. According to Esegbe et al., (2015) there is a limited availability of health services and facilities for neurodevelopmental disorders in Africa. Besides that, the enumerated challenges in the continent can be exacerbated by poor awareness, weak health systems and lack of any institutionalized social support system. Special issues have been identified as confronting management of autism in Nigeria similar to the challenges indicated by the participants, which also include negative attitudinal disposition towards autism. Hence, this shows that there is a rejection of children with autism in special education schools, and lack of facilities, early diagnosis and educational services for autism in health care delivery system.

Community living means being able to live where and with whom you choose, and have a relationship between friends, family and others by (Autism Speaks, t.t). Some parents, they feel ashamed and scared to introduce their autism children to the society. Besides, there are also parents who think it is too early to introduce their autism children to the community (Autism Speaks). They will keep these autism children at home without getting any interaction with the community and the worse situation is that they cannot get a suitable education for them. Either they like it or not, these autism children will have to face the community out there in the future. By exposing these autism children to the community, they can learn how to protect themselves from any dangers. Since more of the young adults live with their parents or guardians, they are less likely to live independently compared to the other peers with disabilities (Ewing, 2013). Therefore, parents play an important role to let and to teach their autistic children to interact with the community so that they can survive on their own.



### 3. Methodology

#### 3.1 Data Source

For this study, the target population was all residents at five residential areas in Senawang, Negeri Sembilan. The sample of this research was 306 of the population of the five residential areas which were 1622. These 306 samples were taken and the questionnaires were given by referring to the table of required sample size on that particular population (Krejcie & Morgan, 2013).

#### 3.2 Theoretical Framework

This study consists of one dependent variable which is the awareness of autism and three independent variables. The independent variables included are the knowledge of autism, role of government and community living. The variable knowledge of autism is included in the research because it will reveal how the knowledge about autism would affect the level of awareness. This is because knowledge about autism might sometimes lead to the level of awareness on autism. It actually depends on what the respondents know about autism. The researchers also decide to query on the role of government into consideration because the researchers want to know whether the respondents know the role of government towards autistic people. If they know what government has done for autistic people, it can be said that they are actually aware of what autism is. Lastly, the researchers also include community living as the last independent variable to check whether it will affect the level of awareness or not. Some parents feel ashamed of having an autistic child. The researchers want to provide knowledge to the society that autistic children also have their own specialty that has a benefit to others. Autistic people also want to live their lives as ordinary people. Community living can help the researchers to achieve an objective of this study. The theoretical framework for this study is shown below:

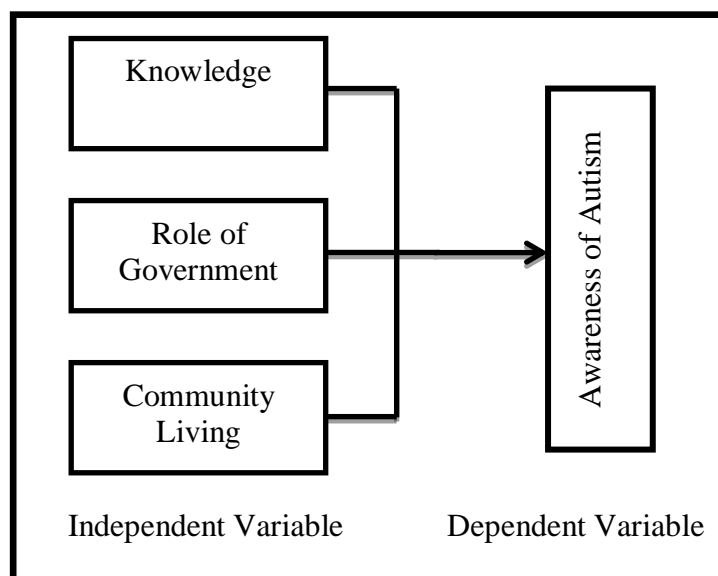


Figure 1: Determinants of Level of Awareness of Autism



### 3.2 Data Analysis Technique

This research used ordinal logistic regression analysis to determine whether all determinants give a significant effect to the awareness of autism among parents. This technique was used instead of linear regression analysis because of the level of measurement in dependent variable is ordinal. Therefore, the ordinal logistic regression is suitable for this research. There are five assumptions to be fulfilled in ordinal logistic regression technique which are; the dependent variable is measured on an ordinal level, one or more of the independent variables are continuous, ordinal or categorical, no multicollinearity exists, and each of the independent variable has an identical effect at each cumulative split of the ordinal dependent variable.

The ordinal logistic regression model is:

$$P(Y_i) = \frac{\exp(\beta_0 + X_{1i}\beta_1 + X_{2i}\beta_2 + X_{3i}\beta_3)}{1 + [\exp(\beta_0 + X_{1i}\beta_1 + X_{2i}\beta_2 + X_{3i}\beta_3)]}, j = 1, 2, \dots, M-1 \quad (1)$$

where;

- P = The probability of successes of each level of dependent variable
- exp = The base of natural logarithms
- $\beta_0$  = The constant of the equation
- $\beta_1, \beta_2, \beta_3$  = The coefficient of the independent variable
- $Y_i$  = The dependent variable
- $X_{1i}, X_{2i}, X_{3i}$  = The independent variables

In this research, p-value of Wald statistical test was used to determine the significant determinants in affecting the level of autism awareness. All p-values were rounded by three decimal places and all statistical tests and confidence interval were performed at significance level 0.05.

Last but not least is the use of Cox and Snell  $R^2$  and Nagelkerke  $R^2$ . The use of this method is to provide an indication of the amount of variation in the response variable explained by the model. The value of this  $R^2$  must be positive and less than 1.

## 4. Findings

### 4.1 Demographic Profiles

**Table 1: Respondents' Demographic Profile**

CHARACTERISTIC	FREQUENCY	PERCENTAGE (%)
Gender		
Male	98	32
Female	208	68
Education Level		
Primary school	9	3
Secondary school	128	42
Diploma	84	27
Degree	72	24
Master/ PHD	13	4
Occupation		
Employed	253	83
Unemployed	53	17
Type of Occupation		
Government Sector	83	27
Private Sector Own	126	41
Business	58	19
None	39	13
Household Income		
< RM800	19	6
RM801 – RM1500	52	17
RM1501 – RM3500	130	43
RM3501 – RM5000	52	17
>RM5001	53	17
Number of Children		
1-2	145	47
3-4	125	41
5-6	33	11
>6	3	1
Autism children		
Yes	8	3
No	298	97
Level of Awareness		
Low	60	20
Medium	184	60
High	62	20

It can be concluded that most of the respondents (97%) do not have autistic children, while the remaining 3% of the respondents have autistic children. The researchers also found out that most of the respondents have a medium level of awareness of autism with 184

respondents. This is followed by high and low level of awareness of autism with 62 and 60 respondents respectively.

#### 4.2 Ordinal Logistic Regression

In order to make analysis of ordinal logistic regression, the assumptions of ordinal logistic regression must be fulfilled first. All the five assumptions to be fulfilled in ordinal logistic regression technique which are the dependent variable is measured on an ordinal level, one or more of the independent variables are either continuous, ordinal or categorical, no multicollinearity exist, and each of the independent variable has an identical effect at each cumulative split of the ordinal dependent variable have been fulfilled before the analysis was done.

According to the methodology described, there were three selected variables to evaluate the awareness of autism. The coefficient, standard error, Wald statistics and p-value for each variable are shown in Table 2.

Table 2: Model Coefficient				
Variables	Estimate Coefficient	Standard Error	Wald Statistics	P-value
Level of awareness (Low)	4.978	1.335	13.905	0.000
Level of awareness (Medium)	7.941	1.393	32.475	0.000
Knowledge	0.261	0.071	13.641	0.000
Role of government	0.141	0.141	6.592	0.010
Community living	0.131	0.131	2.727	0.099

Based on this Table 2, the p-value for knowledge and role of government is less than significance level which is 0.05. Therefore, only knowledge and role of government have significant effect to the high level of awareness among parents.

Table 3: Cox and Snell R <sup>2</sup> and Nagelkerke R <sup>2</sup> Model.		
Model	Cox & Snell R Square	Nagelkerke R Square
Full Model	0.401	0.472

Based on the result obtained above, the full model shows that the Cox & Snell R<sup>2</sup> is 0.401 and Nagelkerke R<sup>2</sup> is 0.472. Hence, it can be concluded that both R<sup>2</sup> value indicate that the total variation of the level of awareness of autism is about 40.1% and 47.2% respectively, explained by all the variables which are knowledge, role of government and community living in the model.

## 5. Conclusion

From the findings of this research, it shows that more than half of the sample in Senawang, Negeri Sembilan has medium awareness about autism. The factors that influence their awareness are knowledge and role of government since the p-value of each variable is less than 5% significance level. As a recommendation, this awareness must be spread to every citizen because according to The National Autism Society Malaysia (NASOM), approximately 9000 children in Malaysia are born with autism every year. Therefore, parents, healthcare providers, educational services and government should double their work in order to develop facilities and programs to spread this awareness.

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