

PREDICTING THE EDUCATION AND THERAPY SEEKING BEHAVIOUR FOR CHILDREN WITH AUSTISM SPECTRUM DISORDER (ASD)

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ABSTRACT

Autism Spectrum Disorder (ASD) is a developmental disability that can cause social, communication, interaction, and behavioral challenges. The case is increased every year, from 15 – 20 children per 10000 newborn on 1990s to 1:100 on 2005. One in 68 children has been identified with ASD according to estimates from CDC's Autism and Developmental Disabilities Monitoring Network on 2012. Children with autism have the same right to grow and develop in accordance with their potential, including obtaining therapy and education. Parents awareness encourage them to seek therapy center for their special needs children. Health Belief Model can be used to predict the factors that drive therapy-seeking behavior in children with autism. This research is a descriptive study with quantitative approach. Samples are parents of children with autism. Locations were selected purposively. Sample represents total sampling of 10 people. Factors that encourage seeking behavior for education and therapy for children with autism are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, and cues to action comes from the symptoms of autism children and the media.

Keywords: Autism; Therapy seeking behaviour; Health Belief Models

INTRODUCTION

Autism has been a health problem that requires special attention and treatment. Autism as explained by Prastowo (2015) is a term that is used to refer to the mental development problem on children which commonly occurs within the first three years of their life and would pick up if further interventions are delayed. Generally, people with autism experience difficulties on communication, social interaction, and limited and repeated desire. Autism is an incurable yet treatable developmental disability.

The total number of people with this type of developmental disability increases every year. References regarding autism before the year of 1990 stated that there were two to five children per 10,000 births suffering from autism. This number escalated in the 1990s decade, where there became five to twenty children per 10,000 births suffering from this disability. The data from Center for Disease Control and Prevention in America in 2001 revealed that the number of children with this disability escalated to 60 children per 10,000 births. In other words, among 167 people, there is one person born with autism. The latest data from CDC in 2012 showed that there are 1 children among 68 others diagnosed with autism.

The tendency of the increasing number of people with autism also occurs in Indonesia. According to the report of World Health Organization (WHO) in 2005, it revealed that the ratio among children with autism spectrum disorder and normal children across the world including Indonesia has reached 1: 100. The autism prevalence in Indonesia in 2013 reached the number of 1.68 per 1000 children below the age of 15. The growing number of children diagnosed with ASD improves parents' awareness in seeking education and health services for children with autism spectrum disorder. In Indonesia, there has been an organization for autism which has started socializing the awareness of autism. Along with it, several therapy centers and schools for children with autism were established. Melly Budiman, a psychiatrist and Head of Yayasan Autisme Indonesia (Autism Foundation of Indonesia) claims that during the years of 1976 – 1985, there were 5 to 7 children being taken care of. Nowadays, the number of the patients who visit for the services is

not smaller than 500 children (<http://www.kompas.com>, March 28, 2006). The number of children with autism in Surabaya in 2006 reached more than 2000 children who were under treatment in 26 autism therapy centers.

Children with autism have the rights to grow and develop with their potentials, including gaining access to therapy and education. Children with autism need to be taken care of with special treatment in order for them to grow and live independently among the society without showing any trace of the remaining symptoms. The improvement of people's awareness of autism, accurate diagnosis of autism prompt the establishment of various therapy centers and special schools for children with autism. Health belief model can be used as a basis to predict the factors that influence parents' decision in seeking treatments and getting access to education for children with autism.

Health belief model is claimed to be established in an attempt to describe particular behaviors and their in relation to health (Smet, 1995). The HBM hypothesis explains that people will not seek either medical attention or disease prevention when they lack the knowledge or relevant minimum motivation regarding health issues, when they regard that one's health condition is not simply dangerous enough, when they doubt the success of medical interventions, and when they encounter issues in performing recommended medical intervention (Muzaham, 1995).

According to Health Belief Model's claim on treatment-seeking behavior, there are four key variables involving in the action are perceived susceptibility, perceived severity, perceived benefits and perceived barriers, and cues to action (Rosenstock, 1997). Health Belief Model can be used to predict the factors that influence parents' decision in seeking treatment for children with autism. The factors are:

1. Factors coming from parents which mainly consist of demographic variables, namely age, sex, race, and sosiopsychological variables, such as socioeconomic level, and peer pressure. The level of knowledge of autism and attitude towards autism are categorized as internal factors coming from the parents.
2. The vulnerability of parents, especially mothers who tend to grow deeper sensitivity when seeing their children grow and develop not as "normal". When recognizing the signs of autism symptoms, a mother would feel as much as pain as the child.
3. The seriousness of parents based on the possibility that children with autism will not grow and develop the way normal children do. Children with autism will likely experience difficulties in the future if they do not get any therapy or go to the appropriate place for school. These difficulties are caused by the lack of independence and peer interaction. The parents' seriousness regarding their worries about their children revolves around their growth and development in the future.
4. The benefits and obstacles/ barriers (according to your term) felt by the parents which can be hope for recovery and independence of the children. The earlier the parents recognize the diagnosis of autism in their children, the sooner they get therapy services, therefore the greater the chance of their children living independently. The hope of recovery and independence may be hampered by some obstacles and sacrifices made by the parents, such as cost, time, energy, physical distance, and social distance in accessing therapy services.
5. The presence of signals and signs is an external factor that allows parents to experience vulnerability, degree of seriousness, benefits and obstacles/ barriers (according to your term) in seeking treatment and special school for children with autism. These signals and signs are indication and symptoms shown by children who are on certain grade or degree of autism. The next signals and signs can come from messages from the information media and reference person, such as advice and suggestions from friends, other family members, or known pediatricians.

Factors affecting the decision of seeking treatment and special education for children with autism can be described by the following conceptual framework :

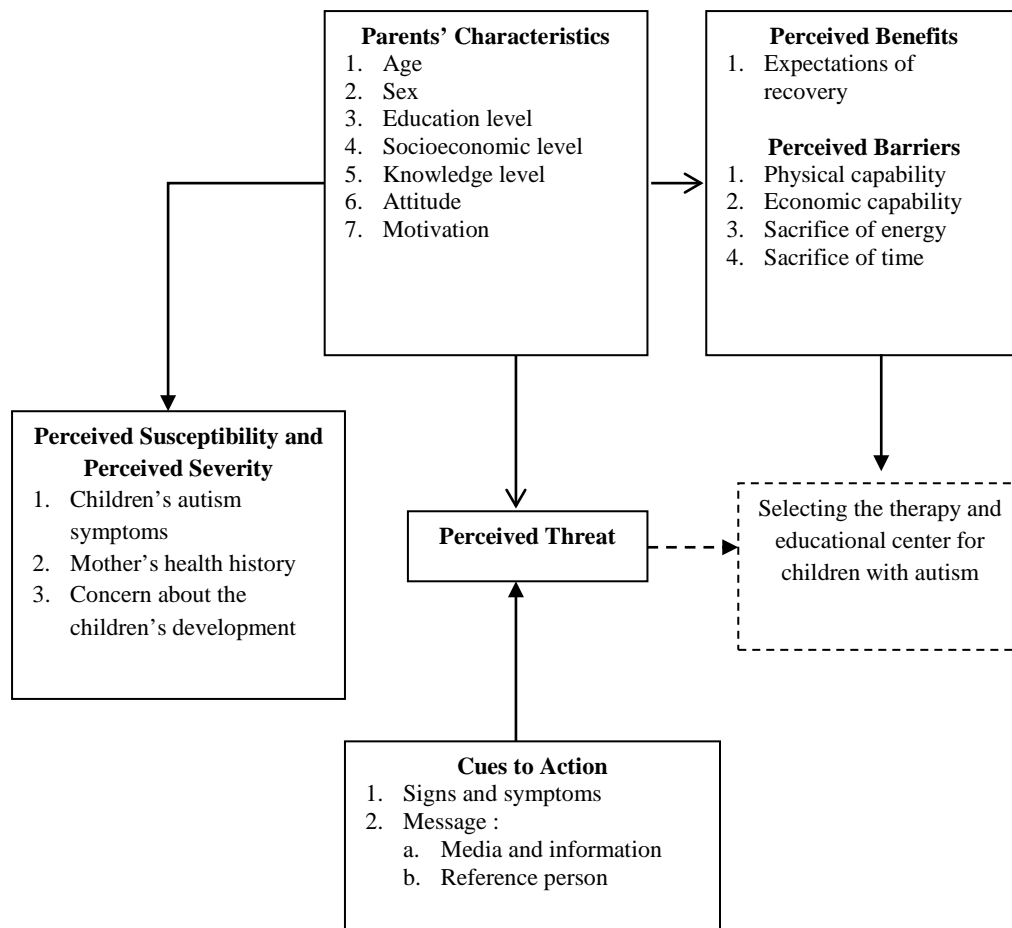


Figure 1.1 Conceptual Framework of the Study
(Source : Modification by Researcher)

Description :

————— = studied variable

- - - - - = unstudied variable

METHODOLOGY

This research is a descriptive observational research conducted using quantitative approach. The study was conducted at School for Children with Special Needs Harapan Bunda Surabaya. The samples were selected from the population that meets the criterion which must be parents who get training therapy at School for Children with Special Needs Harapan Bunda Surabaya. The total population of the samples was 10 people. The data collection was done by distributing questionnaires. The questionnaires were distributed by the school following its rule which is the researcher was not allowed to distribute the questionnaires to the respondents. The filled-in questionnaires answered at school were immediately returned to the school, yet some also brought the questionnaires home without returning them. There were eight questionnaires returned or 80% of the total questionnaires. This has met the requirements of the methodology as the reduction was caused by a problem occurring in the field which the researcher was unable to control. The data was processed by doing editing, scoring, and data tabulation. Meanwhile, the analysis of the data was conducted using frequency table and cross tabulation to reveal the frequency distribution of each variable. The percentage reading of each variable was then elaborated by treatment-seeking behavior towards children with autism.

RESULTS and DISCUSSION

Harapan Bunda School is and educational center for children with special needs, namely those with mental development disorders, such as autism, ADHD, hyperactivity, cerebral palsy, epilepsy, and other mental development disorders. The total number of students enrolled at Harapan Bunda School is 17 children with different health cases. The percentage of students with autism is 58% or 10 children. The respondents of this study are parents whose children are undergoing therapy at Harapan Bunda School. The respondents were selected from the ten samples. However, there were only eight questionnaire or 80% of them returned. This

amount of data has met the requirements of the research method considering the reduction of the total number of respondents was caused by a problem occurring in the field which was unable to be handled by the researcher. All the respondents are mothers of children with autism.

- **Characteristics of Children with Autism and Characteristics of Respondents**

The majority of the children with autism (62.5%) underwent therapy in Harapan Bunda School since they were 0-4 years old, in which 75% of the students are male. Based on the severity of the autism, most of them are less severe. Less severe autism is a condition that children with pure autism do not experience symptoms such as cerebral palsy, epilepsy, hyperactive, and other learning disorders. The characteristics of the respondents based on the age are mature mothers of children with autism whose ages range between 30 to 39 years old (62.5%). The parents of children with autism are educated and have a broad knowledge. It is proven by the fact that most of the parents are university graduates (75%) while the rests are senior high school graduates.

The respondents are well-paid to afford the cost of the therapy and their daily needs at the same time. Most of the fathers work (75%) while for the rests, both the fathers and the mothers work. Half of the respondents' occupations are private employees (50%) and the other half are entrepreneurs (50%). The respondents are quite well aware of autism. It is shown by how most of the parents understand about moderate autism (62.5%) and severe autism (37.5%). All of the respondents are positive about their children's growth and are highly motivated. They also believe that their children's well being is their need.

- **Sociopsychological Conditions which Urged Respondents to Seek for Treatment**

Parents' sociopsychological conditions which urged them to seek for treatment for children with autism are educational backgrounds, knowledge, behaviors, and motivation. In this research, most of the respondents are university graduates. Their educational backgrounds make them open their mind about the importance and the recovery of children with autism. Their broad knowledge allows them to be more aware of the symptoms of autism as early as possible and realize that they cannot be taken for granted since those symptoms will affect the development of the children in the future. It is in line with the fact that most educated parents started the therapy since their children were still 0-4 years old.

The level of their knowledge also allows them to be aware of the severity of autism. The more they know about autism, the more they are aware of the cause, symptoms, and the danger of autism. Parents who understand better about autism will be able to recognize the symptoms of autism rather than those who do not. Knowledge is the result of knowing after someone sensed a particular object. Knowledge is a cognitive aspect that is one of the main reasons which triggers someone to act. Knowledge can be derived from one's own experience and the experience of others (Notoatmodjo, 2003).

All parents showed positive behaviors toward therapy for children with autism. The parents' evaluative process urged them to be positive while handling children with autism. Autism symptoms worried them, hence, they thought that a therapy and an intensive treatment are needed for the sake of their children's growth. All respondents were highly motivated in looking for a good therapy for their children. High motivation, according to Maslow (Gordon, 1993), will arise when an object is deemed as a necessity for someone. All respondents feel that curing the child's autism is achievable when the child undergoes an intensive therapy.

- **Perceived Susceptibility**

Susceptibility that the parents perceived is based on the cause and severity of child's autism. Parents of children with autism who underwent therapy at Harapan Bunda School did not perceive the susceptibility, shown by 50% of parents who were less aware of the susceptibility based on the cause of autism in children since the degree of severity that most children with autism showed was only mild severity. The rest of the parents were aware of it. The cause of autism was mostly because of heavy metals exposure (75%), followed by virus, fungi, and bacterial infection during pregnancy (62.5%), and the use of medicines and herbal medicine during pregnancy (25%).

Perceived susceptibility of the parents of children with autism in Harapan Bunda School is categorized as low and sufficient. The susceptibility perceived is the result of individuals' subjective perception toward the risk of autism. This perception happens because the parents believe that there is a chance of autism occurs because of inheritance, lifestyle, place of living, and the daily behavior of mothers, children, and other family members (Rosenstock, 1997). Susceptibility felt by the parents is not directly affected by their educational background, knowledge, behavior, and motivation. According to Rosenstock, susceptibility happens because of their behaviors. Mild susceptibility was felt by the respondents because they did not realize the connection between family members with autism with the occurrence of children autism. The mothers were not aware of the cause of autism which happened during pregnancy such as infection, difficult pregnancy and childbirth, and consumption of medicines and herbal medicine. There is another cause such as heavy metal poisoning from food and air pollution (Handoyo, 2004). Respondents did not feel such susceptibility urged them to look for a therapy for children with autism. It happened because susceptibility variables in this study were more emphasized on maternal health history, not on the children's susceptibility.

- Perceived Severity

Table 1.1 Respondents' Perceived Severity in Harapan Bunda School Surabaya

Category	Frequency	Percentage (%)
Less severe	3	37.5
Quite severe	1	12.5
Severe	4	50
Total	8	100

(Source : Research Primary Data)

Table 1.1 shows that half of the respondents believed the perceived autism severity could affect their children's growth and development. 37.5% of the respondents did not really feel that autism could affect children's growth and 12.5% of them realized that autism did affect the children's development.

The severity felt by parents of children with autism in Harapan Bunda School is high. Respondents felt that the autism that their children suffered from was serious and they were worried about the future of the children. The severity felt was a perception or individuals' opinion about the severity of the illness along with the effect of it (Notoatmojo, 2003). The perceived severity is based on the effect of the illness. The effects can be physically medical like pain, disability, and death, and also socially such as the effects on family and social relationships with others (Rosenstock, 1997). Severity, which is felt by the parents, comes from the visible symptoms. When there are many symptoms appeared, the mothers are worried, therefore, they look for more information about autism, and sent their children to a school for children with autism along with the therapy. The parents can also sense it because they are anxious about the difficulties that their children will face if they cannot communicate well and be independent. The growth of children with autism is considered to be slower than those who are not suffering from autism. Abnormalities in the center of interaction, communication, socialization, and emotion in the brain of children with autism lead to children being highly selective towards stimuli, less motivated to explore new environments, self-stimulation responses that disrupt social integration, and a unique response to rewards (Handoyo, 2004). This mental developmental disorder affects children's ability to learn and understand etiquette and norms in their surrounding than how they should do (Yusuf, 2002).

- Perceived Benefits

Table 1.2 Respondents' Perceived Benefits in Harapan Bunda School

Category	Frequency	Percentage (%)
Less Beneficial	3	37.5
Quite Beneficial	3	37.5
Beneficial	2	25
Total	8	100

(Source : Research Primary Data)

Table 1.2 illustrates the number of the respondents who did not and did feel the benefits of the therapy for their children for 37.5% respectively. 25% of the respondents found the therapy affected their children's development and recovery. Perceived benefits are individuals' perception toward the benefits of doing certain actions related to health. This benefit may lessen the threat, severity and the danger (Rosenstock, 1997). The benefits that the parents of children with autism got were the possibility of recovery in terms of communication, social interaction, behavior, academic, and independence.

- Perceived Barriers

Table 1.3 Perceived Barriers of Respondents in Harapan Bunda School Surabaya

Category	Frequency	Percentage (%)
Low Barriers	2	25
Moderate Barriers	3	37,5
High Barriers	3	37,5
Total	8	100

(Source : Research Primary Data)

Table 1.3 shows 37.5% of respondents consider that in seeking therapy for their children, they face *rather high* and *high* barriers. While the remaining 25% of respondents face low barriers in seeking therapy for their children's curing and advanced development. Barriers include the distance of the therapy's place from home, the huge cost, the energy spent to treat the children with autism, and the time that should be spared to pay more attention and to help them practicing in the home.

Tabel 1.4 Frequency Distribution of Perceived Benefits and Perceived Barriers

Perceived Benefits	Perceived Barriers						Total	
	Low		Moderate		High		n	%
	n	%	n	%	N	%		
Feeling Less Beneficial	1	12,5	2	25	0	0	3	37,5
Feeling Quite Beneficial	1	12,5	1	12,5	1	12,5	3	37,5
Feeling Beneficial	0	0	0	0	2	25	2	25
Total	2	25	3	37,5	3	37,5	8	100

(Source : Research Primary Data)

Table 1.4 illustrates that 25% of respondents feel that the therapy is helpful and face high barriers. As for the respondents who feel that the therapy is quite helpful and feel that the barriers are in less, moderate, and high are respectively 12.5%. While less respondents feel the benefits of therapy and face low therapeutic barriers and moderate with percentage of 12.5% and 25%. The comparison between the benefits and barriers that respondents perceived in seeking therapy actually shows balanced amounts. The percentage of respondents who are categorized to have moderate and high barriers is 62.5% while the percentage of respondents who feel low and moderate barriers is 62.5%.

The perceived barrier is an individual perception involving sacrifice that should be expended to perform health-related action (Rosenstock, 1997). Barrier in perceiving therapy for children with autism is high, including distance, cost, time, and energy. Notoatmodjo (2003) mentions the benefits of action determine health behavior more than the barriers, related to health action. In this study, the benefits of expectation of curing, advancement, and development of children become a main consideration in seeking therapeutic for children with autism. Any barriers encountered, including the distance traveled, the high cost to be incurred, and the energy to train and pay more attention to the children at home will be done for the sake of the development and advancement of the children.

- Major Signs (Cues to Action)

Signs or major signs are factors that can encourage parents to engage in the act or behavior of seeking therapy and schooling for children with autism. To be able to trigger the parents in seeking treatment for children with autism, the parents, first, need to know about the autism itself. Mass media is the main source of reference for parents to know the initial information about autism (75%). A total of 12.5% of parents learned or knew about the autism from the family while the 12.5% remaining of respondents knew about the autism from health workers or pediatricians.

The main source of information that many parents use to find out about autism is mass media (75%). The use of mass media is due to the nature of mass media that allows respondents to know much about autism through television, newspapers, magazines, radio, internet, and social media. Other sources of information include families and health workers. Some other respondents prefer to find their own initial information about autism before seeking additional information and reinforcement from family and pediatricians. Mass media, according to Snehandu B. Karr (Notoatmodjo, 2003), serves as a provider of information where respondents have the ability to access the media (accessibility of information).

Knowledge of autism, discovering the symptoms of autism seen in children, and the severity of the symptoms strengthen the parents in seeking treatment for children with autism. The study found that most respondents (62.5%) regarded the symptoms and severity of children with autism as the main cue and the first rank signs. Meanwhile, family becomes the second most powerful ranking that encourages respondents to seek therapy for children with autism with the percentage of 37.5%.

The main gestures that encourage parents to seek therapy for their children are symptoms and signs of autism that the child shows. In the next sequence that encourages parents to seek therapy is family. Family is an important person who helped encourage and influence the decision of parents to seek therapy for children with autism. Lawrence W. Green mentions the social support of family as a reinforcement factor that is one of the determinants of therapeutic search behavior as well as the opinion of a pediatrician as a reference person (Notoatmodjo, 2003). The main gestures or signs serve as clues in behaving called cues to action. Cues to action is an external factor of respondents which is useful to get the correct level of acceptance of vulnerability and profit behavior (Notoatmodjo, 2003).

- **Education and Therapy Seeking Behaviour for Children with Autism Spectrum Disorder**

Therapy seeking behavior in children with autism is driven by several factors. These factors interact according to the health trust framework in which the model is developed based on the parental perception of the autism child's healing (Smet, 1995). The perception consists of 4 main things: perception of susceptibility to autism, perceptions of the seriousness of autism based on symptoms and anxiety about the future of the child, the perception of therapeutic benefits for the progress of child development, and the perception of obstacles that must be faced in seeking therapy for children with autism.

These four factors are strongly influenced by two other driving factors. The first driving factor is called modifying factors consisting of educational level, level of knowledge, attitude, and motivation in finding schools and therapy centers for their children. These modifying factors encourage parenting about vulnerabilities, seriousness, benefits, and obstacles. The second factor is the perception of threats that come from outside the individual which is called Cues to action. Cues to action comes from mass media messages, social media, advice from friends or family, doctor's advice, or symptoms of autism that appear from the child.

Autism is still a disorder of mental development that has not been widely known generally by public. Many parents hide the health condition of their children, it showed by the difficulty of conducting direct interviews with parents of children with autism due to the rules of the school to maintain the confidentiality of families and children with autism. Even with the development of communication technology and social media, many people still misunderstand about autism and foster stereotypes that are not true about autism. Therefore, knowledge about causes, diagnoses, signs and symptoms should be encouraged through mass media and social media. Besides, advocacy and social mobilization related to public awareness about autism should be done.

CONCLUSION

The behavior of search therapy for children with autism is driven by perceived susceptibility, perceived seriousness, perceived benefits, and not obstructed by perceived barriers. Therapeutic search behavior is driven by an external factor consisting of signs and symptoms of child's autism, mass media, and reference person such as family and pediatrician's advice. The factors that affect the vulnerability and seriousness perceived by respondents are modifying factors consisting from education level, knowledge level, attitude, and motivation of parents.

Health Belief Models only examines perceptual variables only. Subsequent research can be examined by other variables that are objective and by combining wider theory of behavior. Future research needs to be done with a qualitative approach and the selected location of therapy should be more heterogeneous. Therefore, respondents can obtain a more in-depth picture of the behavior of therapeutic search for children with autism.

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