

Stigma and Knowledge about Autism Spectrum Disorder among Parents and Professionals in Indonesia

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Abstract: This study aimed to explore the stigma and knowledge about Autism Spectrum Disorder (ASD) among Indonesian parents and professionals (teachers and therapists). Data was collected using The Autism Stigma and Knowledge Questionnaire (ASK-Q), which was translated into the Indonesian language. The sample consisted of 125 parents and professionals attending a seminar about autism in Malang, Indonesia. The results of this study indicated that Indonesian parents and professionals in the sample had adequate knowledge of autism and did not endorse the stigma of autism. Results are discussed in terms of their implications for future research and trainings on autism.

1 INTRODUCTION

Three decades ago, Autism Spectrum Disorder (ASD) was considered to be a rare childhood disorder (Lord and Bishop 2010). Currently, ASD has been recognized as “the most common neurological disorder affecting children and one of the most common developmental disabilities” (Leblanc, Richardson, and Burns 2009, 166). The Centre for Disease Control and Prevention’s Autism and Developmental Disabilities Monitoring Network suggest that in 2012 approximately 1 in 68 children has been identified with ASD (Christensen et al. 2016). Although there has not been fixed data on the prevalence of children with ASD in Indonesia, an increasing rate can be clearly observed. The government of Indonesia estimated the number of children with ASD based on the prevalence of children with ASD in Hongkong, which was 1.68 per 1,000 children on less than 15 years old children. As the number of children aged 5-19 in Indonesia reached 66,000,805 in 2010, it was estimated that there were approximately 112,000 children with ASD in Indonesia (Jawa Pos National Network, 2013).

ASD represents neurodevelopmental disorder characterized by difficulties in social communication, along with restrictive and repetitive behaviors and interests (Maye, Kiss, and Carter 2017; Matson, et al., 2012). Autism is referred as spectrum disorder due to the large variability of its

symptoms (Mintz 2017; Reed 2016); some individuals may display mild symptoms while the others display more severe symptoms (American Psychiatric Association 2013). This variability of ASD manifestation may not only appear between individuals, but also within themselves from time to time (National Research Council 2001).

Research has found that there is variability in ASD knowledge across the general population (Harrison, et al., 2017). Inaccurate and/or incomplete knowledge about ASD has been documented in different countries, such as the United States, Lebanon, and Japan (Obeid, et al., 2015; Someki, et al., 2018). In Arab countries, parents tended to rely on cultural interventions involving religious healers, or attributed ASD to vaccines or the “evil eye”, which ascribes one’s misfortunes to “envy in the eye of the beholder” (Obeid, et al., 2015). Among students in Japan, there are misconceptions that autism is not a lifelong condition and it can be outgrown with appropriate treatment, that people with autism have low intelligence and limited empathy, that autism cannot be diagnosed among toddlers, and that one intervention works for all people with autism (Someki, et al., 2018).

Lack of understanding and misconceptions of autism may lead to bullying and exclusion of individuals with ASD, as well as stereotyping or stigmatizing beliefs (Obeid, et al., 2015; Harrison, et al., 2017). Stereotypes towards those who possess

the attributes that do not fit the normative expectations of society often result in negative outcomes including, but not limited to, poor self-esteem and difficulties with employment (Obeid et al. 2015). Greater knowledge about ASD has also been associated with lower stigma (Obeid et al. 2015; Harrison et al. 2017; Someki et al. 2018).

In Indonesia, there are cultural beliefs that problems in pregnancy and/or infancy, breaking the taboos during pregnancy, karma, God's plan, and family size may cause autism (Riany, Y.E., Cuskelly, M and Meredith, P., 2016). Riany, Y.E., Cuskelly, M and Meredith, P. (2016) highlighted that in Indonesian culture, children are viewed as a source of pride for the family and are expected to bring happiness and wealth. Even though further investigation is still required, she suggested that stigma and misconceptions about autism may lead Indonesian parents to neglect their child with autism. These parents may fulfil the child's basic needs without providing adequate stimulation or being emotionally available to the child.

The current study aimed to describe the knowledge and stigma of autism among Indonesian parents and professionals using a psychometrically sound assessment tool. Previous research has explored associative stigma, or stigma attached to the parent of children with ASD (Kinnear, et al., 2016), but there has not many research investigating parents' stigma toward autism. Theoretically, researchers have extended the concept of associative stigma to parent-child relationships within the context of disability stigma (Kinnear, et al., 2016). Exploration of parents' stigma towards autism is required in Indonesian context due to the indication that parents may react negatively to their child with autism. This study also targeted professionals working with children with autism as they play important roles in the intervention/therapy which will affect the efficacy of the result. This study focused on Indonesian parents and professionals who already have interest in autism topics, as these individuals are more likely to have either direct or indirect interactions with children with autism, and thus impacting the lives of these children.

2 METHOD

2.1 Participants

Participants were 126 parents and professionals attending a seminar about autism in Malang, Indonesia. The survey was administered before the

seminar began, to avoid any influence on the participants' responses. One incomplete response was not included in the data analysis, so that the data set consisted of 125 responses. Among the 125 participants, 29 (23.2%) were parents, 68 (54.4%) were teachers, and 19 (15.2%) were therapists. The mean age of the participant was 32.49, almost all of the participants (92.8%) were female, and only 9 participants (7.2%) were male. Most participants (59.2%) had a bachelor degree, while 26.4% finished senior high school.

2.2 Material

The survey consisted of a section on participants' demographic information and the ASK-Q (Harrison et al. 2017). The ASK-Q has been shown as a psychometrically sound assessment tool to assess knowledge and stigma of autism (Harrison et al. 2017). It is comprised of 49 items which are organized into four subscales: diagnosis, etiology, treatment, and stigma. Participants were asked to respond to the statements by selecting "Agree", "Disagree" or "Don't Know." According to the scoring protocol, "Don't Know" answer choice was coded as incorrect, regardless of the true correct answer. Some examples of the ASK-Q items are: some children with autism do not talk, autism is preventable, there is currently no cure for autism, autism is a result of a curse put upon/inflicted on the family. ASK-Q items were selected based on ratings of face, construct, and cross-cultural validity by a group of 16 international researchers. Using Diagnostic Classification Modeling, Harrison, et al. (2017) confirmed the proposed factor structure and evaluated the statistical validity of each item among a lay sample of 617 participants.

For the stigma endorsement subscale, a correct item score is equivalent to not endorsing the stigma. A scoring template developed by Harrison et al. (2017) was used to gain participants' subscale and total scores. The subscale scores were then compared to the cutoff scores to identify adequate/inadequate knowledge and stigma endorsement/lack of stigma endorsement (Harrison et al. 2017).

For the purpose of this study, the ASK-Q was translated into the Indonesian language using a backward translation approach. The forward translation was done by the second researcher, while the backward translation was done by a professional translator. Both researchers reviewed the final draft before being used for data collection.

3 RESULT

The result of this study indicated that Indonesian parents and professionals in the sample had adequate knowledge of autism. Among the knowledge subscales, the diagnosis subscale had higher mean score than the etiology and treatment subscales. Examination on participants' individual scores showed that 93.65% of participants (N=118) had adequate knowledge on the diagnosis of autism, while 64.29% of participants (N = 81) had adequate knowledge on the etiology of autism, and 70.63% of participants (N=89) had adequate knowledge on autism treatment. Sixty-two participants (49.6%) had adequate knowledge in all three subscales.

Table 1: Participants' Mean and Standard Deviation Scores.

Subscale	Mean (SD)
Diagnosis	13.76 (1.87)
Aetiology	11.27 (1.98)
Treatment	10.52 (1.57)
Stigma	2.93 (1.37)

As described in Table 1, the mean score for stigma subscale was 2.93, indicating that participants in this study in general did not endorse stigma about autism. Eighty participants (63.49%) did not endorse stigma about autism, but 45 participants (35.71%) endorsed it. A detailed description of participants' endorsement for each autism stigma is described in Table 2. As showed in Table 2, most participants did not endorse the stigma related to the preventability of autism and problems with aggression. However, most participants endorsed stigma in relation to etiology of autism; that autism is a result of a curse, cold or rejecting parents, or traumatic experiences.

4 DISCUSSION

This study aimed to describe the knowledge and stigma of autism among Indonesian parents and professionals. Results indicated that Indonesian parents and professionals in the sample in general had adequate knowledge of autism and did not endorse the stigma of autism. Despite the adequacy of participants' knowledge on all subscales, higher mean score was reported for knowledge on the diagnosis of autism, followed by etiology and treatment of autism. In regards to autism stigma, the result of this study indicated that Indonesian parents and professionals tend to endorse stigma in relation to etiology of autism; that autism is a result of a curse, cold or rejecting parents, or traumatic experiences.

These results suggested that there have been sufficient training and seminars focusing on the diagnosis of autism in Indonesia; however more information on the etiology and treatment of autism is required. Previous studies have shown that even a limited amount of training can increase participants' knowledge about ASD, and lessen autism stigma (Obeid et al. 2015; Someki et al. 2018). Participants' endorsement toward the stigma around the etiology of autism may also be influenced by their cultural and religious background, although further study is required to examine this matter.

There are several limitations that should be considered in interpreting the results of this study. First, the participants of this study were attending a seminar about autism. This may indicate their specific interest in the topic, as well as some background knowledge about autism. Almost all participants mentioned that they have heard about autism, thus their adequate knowledge on all subscales may not represent those of the general

Table 2: Participants' Endorsement for Autism Stigma

Stigma	Endorse	Not endorse
Autism is preventable.	39.2%	60.8%
All children with autism usually have problems with aggression.	26.4%	73.6%
Most children with autism are extremely impaired and cannot live independently as adults.	55.2%	44.8%
Autism is a result of a curse put upon/inflicted on the family.	96.8%	3.2%
Traumatic experiences very early in life can cause autism.	63.2%	36%
Autism is caused by God or a supreme being.	52.8%	47.2%
Autism is due to cold, rejecting parents.	83.2%	16%

population in Indonesia. Second, this study only involved participants from certain areas in Indonesia. Future study should incorporate larger samples from various areas in Indonesia to be able to properly evaluate the psychometric property of the Indonesian version of the scale.

In short, this study was a first attempt to employ the ASK-Q in an Indonesian sample. Results indicated that Indonesian parents and professionals in the sample in general had adequate knowledge of autism and did not endorse the stigma of autism, although many participants endorsed stigma related to the cause of autism. These findings suggest that more comprehensive trainings or seminars on autism should be offered to Indonesian parents and professionals. These trainings should not only cover topics around the diagnosis of autism, but also the etiology and evidence-based treatments of autism.

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