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The Meaning of Having An Autistic Child in Malay Family Indonesia

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Abstract

The condition of families with autistic children raises many views and judgments both from family and society. This ethnographic study aimed to describe the meaning of families and communities towards families with autistic children. Data were collected through focus group discussions and in-depth interviews. Key informants come from families who have autistic children and community members recruited by purposive sampling, while the data were analyzed using thematic analysis. This study results generate two categories of perception of the meaning of having autistic children. The first category was made by the families which comprises four themes such as 1) A test from God, 2) Destiny of God, 3) Autistic children different with other children, and 4) Children who need intensive helping. The second category was the perception made by the community members which consists of two themes, such as 1) Test for family, and 2) An autistic child as a holy child. This study further shows that culture is believed to determine how families and the members of the community perceive and interpret the existence of autistic children in the families so that it is very important for health workers to understand the culture that exists in the community.

INTRODUCTION

Autism is defined by the World Health Organization as a part of Autism Spectrum Disorders (ASDs) along with other disorders such as childhood disintegrative disease and Asperger syndrome. As the root of such condition, specifically ASDs belongs to a neurodevelopmental-disorder which is signed by three main deficit domains happening in social interaction, communication, and repetitive or stereotypic behavior, and restricted interest (World Health Organization (WHO), 2013). Particularly, in Indonesia children with autism belong to the category of children with special needs. Children who have special needs are seen as the ones who have li-

mitations or extraordinarinesses in terms of phisic, mental, intellect, and social ability. Having a child with special needs cannot considered as a disaster but a mandate from God in that parents, family and society members are responsible for caring for them. In Indonesian neighbouring country like Malaysia, autistic children are considered as “Orang Kurang Upaya” or less efficient people, or in Malay it means less capable people. Likewise, In Chinese the phrase means a disease of loneliness, while people in Taiwan believe that children with autism as the ‘Sons of Stars’ which means such kind of children are coming from alien domains whose world differs from ours (Kok & Gan, 2012).

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Children with autism in some countries has increased steadily. For example, in the United States alone a survey data generated by the Center of Disease Control and Prevention claimed that in the period between 2011 and 2013, 1 out of 80 children suffered from autism while the figure has significantly become 1 out of 45 children in 2014 (Zablotsky et al., 2015). While in Indonesia, data records regarding the number of children suffering from autism are not yet available. However, in 2013 there were an estimated more than 112,000 autistic people in Indonesia with ages ranging from 5 to 19 years. In 2015, the estimated children with ASD were about 1:250, in which there were approximately about 12,800 children suffering autism (Judarwanto, 2015). Particularly in Pontianak, West Kalimantan, the ethnic Malay group has the largest population. The 2016 profile of Bina Anak Bangsa Special Needs School Pontianak City recorded that there are about 356 children with autism comprising 280 children who are taking therapy programs in Pontianak Autism Center and 76 autistic children have enrolled into a Special needs School in Pontianak City, and 46.05% of those 76 students are from Malay ethnic families.

The prevalence figure shows an increase annually, but the cause of autism is still unclear. Nevertheless, most scientists claim that ASD is a complex disorder, and there is no single cause of it, for no expert knows for sure what causes autism. However, they assume both genes, parents characteristics, conditions during pregnancy, and the environment play a potential role in causing a child to be more likely to suffer from ASD (Hernawan et al., 2018; Centers for Disease Control and Prevention (CDC), 2016). Autism appears in children regardless of ethnicity, race, religion, social status, and family income and level of education. However, each tribe has a different meaning about having an autistic child (Dyches et al., 2004). According to Hwang & Charnley (2010) claim that Koreans believe that autism is a punishment for the sins the family did in the past like a mother who neglected her child. However, in some countries, parents believe that having an autistic child is a will of God (Al-Aoufi et al., 2012; Goin-Kochel et al., 2014; Riany et al., 2016).

It is important for nurses and health workers to know the meaning of having autistic children for families because by knowing how families give meaning to having autistic children, nurses and health workers can provide and develop nursing interventions and innovations based on various cultural differences, values and beliefs that exist in society. Subsequently, they can implement a cultural approach in a community when providing nursing care for individuals, families, and communities in accordance with the existing cultural backgrounds and

beliefs. In a line with the results of previous studies, it is argued that the culture adopted by families with autistic children affects the families in terms of accepting child, making decision, or seeking treatment (Mandell & Novak, 2005; Ennis-Cole et al., 2013). Beside that the culture also will influence emotional well being and social life in the family (Pitten, 2008; Gobrial, 2018). In this regard, Malay people who are predominantly muslims cannot be separated from Islam. Thus, the cultural views of Malays regarding the meaning of having autistic children are influenced by Islamic teachings. This study aims to describe the meaning of having autistic children in families who come from a Malay background and the community where they live in accordance with a Malay cultural perspective.

METHOD

An ethnographic design was used in this study. The ethnography is a qualitative research methodology that identifies behavior, interaction, and perception of what is happening in families and community in relation with children with autism. This study was carried out in the Pontianak Autistic Center, a Mental Health Hospital, and a Special Needs School, as well as family with autistic children in Pontianak City, West Kalimantan Province, Indonesia.

The key informants in this study consisted of 20 families consisting of 19 mothers, 16 fathers, 5 grandparents, and 7 grandmothers who came from nuclear families, extended families, families of single mothers and families of grandparents who lived with their grandchildren who suffered from autism. The inclusion criteria in the selection of the key informants are families who have children with autism, the age of children under 18 years old, and come from Malay ethnic families. While the exclusion criteria in this study were families with autistic children aged over 18 and not from Malay ethnicity. In addition, families with autistic children who at the same time experience other special needs problems such as mental retardation. Not to mention, key informants who suddenly refused or did not want to become participants when the research was being conducted. The second key informants consisted of 1 community leader and 2 religious leaders. These key informants are knowledgeable about autism and directly interact with families and children with Autism. The key informants are selected using a purposive sampling method.

The techniques used to collect the data in this study were site-observation, focused group discussion, and in-depth interview. The researcher observed participants in the autistic center, mental health hospital and at home. In addition to participant

observation, the researcher conducted in-depth interviews with key informants such as parents of children with autism, and grandparents who have grandchild suffers from autism. The researcher also conducted in-depth interviews with 1 community leader and 2 religious leaders in the community who knew about autism and interacted directly with families with autistic children. Data were collected using both a tape recorder and field notes. In Focused Group Discussions (FGD) the researcher divided the key informants into four discussion groups based on the level of education of key informants. The father and mother group of autistic children are divided into 2 groups, who graduated from high school and undergraduate education backgrounds. While each of grandfathers and grandmothers has one FGD group. Each FGD took place with a duration of about 45-60 minutes and each FGD group consisted of 6 key informants. The interview in this study was conducted by the first author without involving any observers or assistants. The FGD was held closely in one of the consultation rooms in the Autistic Center. To maintain confidentiality the researcher did not allow anyone to enter the room during the FGD. Before starting the FGD the researcher explained about the research objectives, the benefits and impacts of the research, as well as the rights of key informants. Key informants can withdraw or resign if they object to participating in this research. After the explanation, the researcher also requested the key informants to sign the consent form if they agreed to participate, as proof of their willingness and agreement to participate in this study voluntarily.

The instruments used in conducting in-depth interviews was interview guidelines developed by the researcher based on the research objectives. Some examples of main questions based on interview guidelines include 1) what was the meaning of the presence of an autistic child for your family? 2) how did you view your child who have autism? 3) what did your family members believe of the meaning of your child's autism? 4) What were the Malay cultural views related to families and children with autism? The researcher has tested the validity test of the questionnaire by first of all conducting a credibility. Before designing a research instrument to be used as an interview guide, the researcher firstly conducted participant observations of family and child activities at home, at an Autistic Center and at the hospital where the family carries children for therapy. The participant observations lasted about 6 months. During participant observation activities, the researcher interacted with participants and confirmed and clarified data found as a form of member checking. In addition to the participant, the re-

searcher also conducted peer checking. To get high credibility, the researcher triangulated data obtained from key informants through in-depth interviews, FGDs, and participant observations.

Data was analyzed with thematic analysis technique. According to Braun & Clarke (2006), thematic analysis consists of six stages including transcribed all audio recorded interview data verbatim, coding, searching for themes, reviewing themes, defining and naming themes, and the 1st process is to write up. In the first stage the researcher first of all transcribed all audio recorded in Indonesian. The Indonesian transcripts were then translated into English by the help of an Indonesian-English translator who is bilingual (Indonesian and English) in order to ensure the translation accuracy. The researcher re-read the translation results and made crosschecks so that the translation results are truly transcribed in accordance with what were expressed by key informants. In the second stage the researcher conducted coding for the transcribed results. It was done by identifying the data considered to be related to the research questions and then encoding all data items line by line. In the third stage, after doing the coding the researcher then created sub-themes which were grouped into themes. The themes were then classified by categories which come from each group of the codes. Finally, in the last stage, the researcher carried out the writing up of the entire study finding. All process of stages in analysing the data was carried out manually in Microsoft Word document.

This study has been granted an ethic agreement issued by Institutional Review Board (IRB) of Khon Kaen University Thailand number HE602175. Rigor was ensured by observing key principles of qualitative interviewing consistent with ethnography, such as building trust and good relationship with the key informants. The researcher also conducted members-checking to confirm the results of interpretation with 50 key informants.

RESULTS AND DISCUSSION

Family's perception toward children with autism

This study found four themes about the meaning of having autistic children in Malay family based on families' perspective, the four themes include 1) a test from God, 2) destiny of God, 3) an autistic children different from other children, and 4) children who need intensive helping.

Theme 1: A Test from God

Having an autistic child is believed by families as the test from God. This is a positive meaning felt by the family because God tests their level of patience. So, if the family passes the test, the family can accept the child and nurture their autistic children

patiently, as expressed by one of participants as follows:

“It clearly takes an extra patience to clean and tidy up the house when looking after my son. Moreover, as his mother, I try to open my heart and my mind to accept my son’s condition as a test as well as a blessing from God. It is to test our patience as parents in taking care of our child, Sir” (Mother aged 34 years old, autistic child aged 6 years old)

Theme 2: Destiny of God

According to the families having an autistic child has become the destiny of God that must be accepted. What happens to the family is God’s unavoidable will. It is God who regulates everything and families are not given the choice to choose what kind of child they wish to have, but accept the reality as a destiny. Families who believe that having autistic children as destiny or plan of God are families that have a positive outlook on God’s will, as revealed by one of participant as follows:

“What can I say, Sir. What should I do other than accepting and attempting to cope with it. Maybe this has been a destiny from God, even if I could choose, I did not want to have a child with autism, no mother who wants to have abnormal child, but this destiny is granted by God, and it is God’s will” (Mother aged 44 years old, autistic child aged 14 years old)

Theme 3: Autistic children are different from other children

Families who have negative judgments or views on autistic children see autistic children as children who are different from other children, and these families tend to compare their children with other people’s children. This difference is felt by parents when they compare their autistic children’s ability to the ability of other children. For example, mothers felt that when their children reached 3 to 4 years old, the children still could not speak. All types of families involved in this study felt that their children are different from other children of their age as revealed by one of participants in these following expression:

“At age of 4 he still cannot talk. He can walk when he was 2 years old, but he just walks tiptoeing, even until now. He likes to beat himself, Sir. he taps his mouth with his hands, and sometimes wounds it, he taps it like this (showing an example of her son tapping his mouth with his hand). And he is very hyperactive, if this door is open, he can run everywhere, Sir” (Mother aged 34 years old, autistic child aged 7 years old)

Theme 4: Children who need intensive help

Negative views on children with autism arise

from the families who feel their autistic children need intensive assistance in order to meet their basic needs. The autism condition experienced by the children causes some autistic children very dependent on caregivers. According to mothers who have children with autism, an autistic child needs help to carry out her/his daily activity cares because the autistic child has not been independent yet, as expressed by one of participants as follows:

“My daughter is 13 years old, but to do anything, she still needs help from either by me or by her nanny. It’s just like taking care of a 1 or 3 year-old-child who needs help to do anything she needs. She still needs help when taking a bath, eating meal, or her meal will be wasted if we don’t help her. And, if she takes shower by herself, she can spend 1 hour in the bathroom, day dreaming, talk alone, and sometimes she doesn’t want to put on her underwear. When defecating on her pants, sometimes she puts the dirt at the wall or floor” (Mother aged 32 years old, autistic child aged 13 years old).

Community’s perception toward family and children with autism

There is a wide range of perceptions coming from a number of community leaders about families with autistic children and the autistic children themselves. The community leaders have positive view on families who have autistic children. They believe that having an autistic child is a test for the family, and the community leaders also consider an autistic child as a holy child. Thus, there are two themes found in the category of perceptions of community leaders on families and children with autism such as 1) test for family, and 2) autistic children as a holy child.

Theme 1: Test for family

Community leaders see that having an autistic child is a test from God for the family. The leaders believe God tests the family to see the level of patience of parents in caring for their autistic children, as expressed by one participant as follows:

“Speaking for me, all children are a test for their parents. Especially for the parents with autistic children who are usually called children with special needs. Whether or not parents patiently to take care of their autistic children. Of course, the test given to them is harder than the test given to parents with normal children. God wants to see if the parents can take it or not, whether the parents can take care of their autistic children or not. If they are able to take care of their autistic children, God will ease their way and fortunes because anything is coming only from God” (community leader)

Theme 2: An Autistic child as a holy child

In the view of Islamic religion, children with special needs such as autistic children are born in a pure and in clean state. Some reasons, according to the views of community leaders, are because children with autism experience limited thoughts and common sense which results in them not knowing what they may or may not do, as revealed by one of participants as follows:

"In my view, a child with autism is categorized as a holy child. Meaning, this kind of child in front of Allah gets dispensation for mistakes or sins that he or she has committed due to their limitations or intellect and common sense. Even though they might grow well physically, but their mental development and brain experience obstacles. They speak little so that they commit less sin and mistakes. If they make mistakes it is just because they do not understand what they are doing, which one is allowed, which one is polite or is not polite. They do not understand it" (community leader)

Test from God

In this study, the researcher did not find different perspectives from family and society about the meaning of having an autistic child. Both family and community group see autistic children as a test from God for families. Accordingly, the results of this study are not much different from the results of some previous studies on the meaning of having autistic children in various Muslim majority countries. For example, like what is stated by Jegatheesan et al. (2010) about Autism from the perspective of Muslim Immigrant Families in South Asia, as well as Tait & Mundia (2012) in their study on Muslim parents with ASD children in Brunei argue that the families believe that having an autistic child is a test and destiny from God. The same perspective is also believed by parents in Iran who have autistic children, they understand that having an autistic child is a test from God (Samadi & McConkey, 2011)

In Islam itself, it is believed that a test from God can be in the form of pleasure as stated in Quran, Surah Al-Anfal verse 28 saying "And know that your properties and your children are but a trial and that Allah has with Him a great reward". This test means testing how grateful Muslims are and how much they praise God when they are given a test of pleasure. The second form of the test is in the form of sadness. Through having an autistic child, a family is considered to get a sadness test from God. This test aims to see how patient the family is in receiving a test of sadness.

Thus, if the family has sufficient patience, the situation must have a positive impact on the family in caring for their autistic child. Meanwhile, if the

family loses patience, having an autistic child will have a negative impact on that family in terms of child care.

Destiny of God

In this study the researcher found that families interpreted having autistic children as destiny from God. The study also confirms that parents have no choice whether to either accept or reject autistic children given by God. Thus, the results of this study confirm the results of several previous studies in which participants were Muslim, for example, a study by Gobrial (2018) in Egypt which found that mothers in Egypt believed that autistic children were blessings and gifts from God. Correspondingly, Donald (2015) argues that parents who have autistic children have no choice but to accept God's decision. Definitely, the results of this study are supported by previous researchers like Jegatheesan et al. (2010) who argue that autistic children are God's destiny for the family as well as a gift from God for the family.

According to the teachings of the Qur'an, God bestows on certain families autistic children because God believed the families have the ability to care for their autistic children. God will not burden His people beyond their abilities, and for this reason God chooses certain families who are considered capable of receiving His gifts.

Thus, if the families can accept the existence of such a child in their families, they are responsible for caring for the children even though it is financially deprived. The families do not even need to care about what other people say about their children's condition, but instead Qur'anic teaching encourages them to surrender to God who gives the mandate.

Autistic child as a holy child

The results of this study indicate that community leaders have different views with families about the meaning of having autistic children. Community leaders view autistic children from the positive aspect in which autistic children are holy children. The community leaders also believe that children are liberated by God from all kinds of wrongdoing or sin made due to the limitations of their common sense. This opinion is in line with what was revealed by Shaked & Bilu (2006) in the results of their research which believe that autistic children are pure and innocent children given by God to their families so that families need to protect and look after their children properly.

According to Islamic teachings, as written in the Qur'an, every child born in a sacred situation or "fitrah" and as long as they are children, they are still the responsibility of parents in terms of caring for,

nurturing and raising children. In the case of a child with autism, some children cannot think normally because they have neurological development abnormalities. Thus, religious obligations do not apply to them, regardless of their age, and are freed from all sins committed. Thus, the family's duty is to care for them during their lifetime.

Autistic children are different from other children

The findings in this study note that autistic children according to family perspectives are children who are different from other children. They found differences when their children were 3 to 4 years old. During that age period their children showed behavior that they could not speak, they liked to beat and hurt themselves. They were also hyperactive, and sometimes went tantrum. Some studies support this finding that autistic children differ from other children, as stated by Greaves et al. (2006) argue that when autistic children come together with other children, their differences in behavior is that they appear to be engrossed in rituals and routines themselves. They have a ritual to play alone with one type of game. The other differences in behavior in autistic children according to other researchers such as showing flat facial expressions, lack of interest in certain objects, smiling or laughing alone, getting angry for no reason, lack of responsiveness to hugs and aloofness, and this apparent behaviors appear at the age of 2 up to 3 (Nuner & Griffith, 2011). Whereas from the language ability aspect, the striking difference is that they experience speech delay or are very late to speak or cannot communicate at all, and the language they use cannot be understood. Therefore, in this case, children have difficulty to communicate and do not use language to communicate (Scheuermann & Webber, 2002; Nuner & Griffith, 2011).

Autistic children are unique children and they are not like other normal children because autistic children experience obstacles in communication, socialization, and behavior whose symptoms begin to appear in children before they reach 3 years old. The family view that autistic children are different from other children indicates that autistic children need extra special attention and treatment from the family in caring for and meeting the needs of children compared to other normal children.

If the family views the difference in autistic children positively, the family will accept the opposite difference. On the other hand, if the family views the difference negatively, it will make the family respond negatively to the presence of an autistic child in a family such as denial, shame and hopeless.

Children who need intensive help

This study found that autistic children need intensive help from families. Autism condition experienced by children makes autistic children dependent on family as caregivers. They need help to carry out daily activities such as bathing, eating, dressing, and cleaning themselves after elimination or excretion. The inability of a child to rely on himself in carrying out basic daily activities is caused by a disable or incomplete sensory responses and motor complications, especially problems in their fine motor skills (Jasmin et al., 2009). The findings of a study by Graetz (2010) in adults with autism support one of the findings in this study that an individual with autism will need assistance of others in carrying out basic activities throughout their lives. In this case, Graetz has proven in his study that even adults with autism still need help in carrying out daily activities such as defecation, bathing and wearing clothes. Graetz study finding was supported by Gorsky (2014) saying that the older the age of the child is, the more physical self-care are carried out by parents for their children. It is obvious that the obstacles in cognitive abilities in children make it difficult for children to do daily living skills. However, slightly different from this study finding, study on general daily care in autism children in Vietnam found that the caregivers only need to help the autistic children do general daily cares such as eating, drinking, bathing, and brushing teeth (Anh, 2015)

Autistic children show different abilities in fulfilling basic self-care. Some have to be assisted fully by family and the level of assistance necessity depends on the condition of autism or the severity of autistic disorders experienced by children. This is reinforced by the opinion of Bal et al. (2016) about daily living skills in individuals with autism spectrum disorder. Their study's results shows that the ability of autistic children to meet their daily needs is lower than those who are diagnosed with other non-spectrums. This condition is affected by impaired nonverbal cognition and severity Autism Spectrum Disorders symptoms experienced by children.

Therefore, families must be able to see the abilities and potential of their children in meeting their basic daily needs. They also need to teach children to carry out their daily life activities so that little by little their children can do the activities themselves, and in the end they may be partially or even fully independent so that their dependence on the family decreases.

CONCLUSIONS

There is no difference between family perceptions and community leaders' in terms of seeing or interpreting children with autism from the point

of view of Malay culture. Values and beliefs of Malay culture itself are strongly influenced by Islamic teachings. Therefore, the results of this study show positive views of families and community leaders towards autistic children. First, children with autism are God's tests and destiny for families, and autistic children are holy children. Second, the situation of having autistic children makes families more patient in caring for and their raising children. Nevertheless, the negative views also arise from the families about the meaning of having autistic children, such as autistic children are different from other children and autistic children need intensive assistance from their family.

Therefore, It is important for nurses and health workers to understand the practices and nurturing culture of autistic children in families with different cultures, values and beliefs. Differences in the meaning and views of autistic children can affect family acceptance and important decisions made by families regarding their children, including handling children both at home and in the community. Nurses and health workers must ensure that the family can properly care for the child by fulfilling the basic needs of the child such as affection, attention and basic needs of the child. Nurses and health workers can collaborate with parental support groups, community leaders and religious leaders in providing information, education and counseling for families. Nurses also can develop innovations and nursing interventions in implementation nursing care that is in accordance with the culture of the local community.

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BADAN KOMITE ETIK PENELITIAN
PUSAT PENELITIAN, PENGABDIAN KEPADA MASYARAKAT & INOVASI
**SEKOLAH TINGGI ILMU KEPERAWATAN MUHAMMADIYAH
PONTIANAK**

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**SURAT KETERANGAN LOLOS KAJI ETIK
(ETHICAL CLEARANCE APPROVAL)**

Nomor: 168/II.1.AU/KET.ETIK/V/2019

Komite Etik Penelitian Sekolah Tinggi Ilmu Keperawatan Muhammadiyah Pontianak yang terdiri dari:

Dr. Suriadi, MSN

telah mengkaji dengan teliti proposal berjudul :

“The Meaning of Having An Autistic Child in Malay Family Indonesia”

Nama peneliti utama : **Cau Kim Jiu**
NIDN **1121057802**

dan telah menyetujui proposal tersebut.

Pontianak, 5 Maret 2019

Ketua Komite Etik Penelitian
STIK Muhammadiyah Pontianak

Dr. Suriadi, MSN., AWCS
NIDN : 1103076601