

Family Management of Autistic Children in Malay Families Indonesia

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Abstract— *The way families handle their children who experience Autism varies from one family to another, which is clearly influenced by the culture adopted by each family. This ethnographic study aimed at describing family management on autistic children in Malay ethnic in Pontianak city, Indonesia. Data was collected through focus group discussions and in-depth interviews from key informants consisting of 20 Malay families who have autistic children. Those were recruited by a purposive sampling method. The collected data was then analyzed using thematic analysis. There are three themes found in this study, 1) women act as primary caregivers, 2) men managing autistic children, and 3) family seeking help. This study was also intended to show the culture, values, and beliefs adopted by families to determine how families manage and deal with autistic children in their homes. It is important for nurses and health workers to understand the cultural diversity that exists in the community. Thus, they can provide nursing care for each family tailored to their respective cultures and beliefs so that autistic children can grow optimally.*

Keywords— *Family management, children with autism, malay families, indonesia.*

I. INTRODUCTION

Autism is a collection of neurodevelopmental disorders known as Pervasive Development Disorder (PDD). This disorder is characterized by three major disabilities in children such as impaired speech and communication, disorders and limitations in social relations, and disruption of repetitive behavior patterns and interests, as well as stereotype.¹ Autistic disorder issue is viewed as a solitary element and transformed into a scope that covers all prevalence of inescapable developmental disorder, except the Rett's disorder. Thus, to identify this disorder children are examined on each of two areas related to the dysfunction, for example, disability to interact socially and stereotyped conduct.²

The revealed pervasiveness rates of autism and its related impairments have been expanding worldwide over the previous decades, from around 4 out of 10,000 to 6 out of every 1000 children.¹ In spite of the fact that in Indonesia there is no official information on autism cases in children revealed by the administration. Nevertheless, in 2013 it was assessed that there were in excess of 112,000 autists in Indonesia whose ages range from 5 to 19 years. While in 2015 the assessed number of children with ASD was around 1: 250, or approximately 12,800 children experienced autism.³ In 2016 there were 365 autistic children discovered based on the results of an observation held at the Pontianak Autistic Center. Of those children 280 took a therapy program at the Pontianak

Autism Center, while 76 autistic children were attending special needs schools. Forty-six point five percent (46.5%) of autistic children served at the autistic center came from Malay ethnicity family background. Therefore, the focus of this study was on families with autistic children who come from Malay ethnicity background.

Autism Spectrum Disorders is a lifelong disorder experienced by children with varying degrees of severity from one child to another, so that management needed to deal with autistic children also varies from one child to another. Some children have mild symptoms, and only a few who need helps from their family to carry out their basic needs activities. They can speak despite the difficulty in maintaining two-way communication with others. However, there are also children whose symptoms are very severe and need extraordinary support from the family.^{1,4} This might be a special challenge for families in dealing with children with autism at every stage of their life journey or life cycle.⁴ In this case, families must be able to adapt to existing life situations including adjusting to handling children at home.⁵ Meanwhile, handling of autistic children is influenced by culture, values and belief systems that exist in the family. Where the culture and system of belief embraced by each family reflects the views and ways of the family in regulating family life and the roles they perform.⁶

In caring for autistic children, parents must adapt to the needs of their children so that specific strategies are needed to meet the needs of their children. In the meantime parents can also carry out their daily routines such as working.⁷ The results of previous studies conducted by Schaaf and colleagues state that morning routine is the most difficult and busiest routine for parents to manage children. Since it coincides with the preparation of parents to work, while at the same time parents also need to prepare their children to meet their basic needs that range from toilet needs, bathing, eating meal to preparing school needs.⁸ In addition, parents have a major role in handling children at home and train children to be able to meet their needs independently.⁹ This is in line with the research finding by Jiu and Rungreangkulkij that assert that a mother is the main caregiver at home for children who have autism. They further affirm that various ways are done by the family in dealing with autistic children at home starting from controlling eating patterns, helping to meet basic daily needs such as bathing, dressing, cleaning themselves after defecation.¹⁰

Accordingly, managing children is not only a responsibility of a mother, but all family members should take

a part in fulfilling the caring task. Which applies to both nuclear family and extended family. However, in reality women, mothers and grandmothers and female siblings, act as the primary caregivers of children at home.¹⁰

Therefore, the findings of this study might be beneficial for nurses and health workers because they can help people who are directly involved in providing basic care for their autistic children. In other words, medical staff can find out how families manage autistic children at home based on a cultural approach because each family has different ways of managing children with autism. This paper is part of the results of a research dissertation whose purpose is to describe and explore family management in autistic children in ethnic Malay families.

Cultural diversity in Indonesia influences the way families manage their children with autism. One example is what happens to ethnic Malay families who have their own ways of managing children with autism. This condition is worthy of being known and understood by nurses and health workers so that they can apply the practice of nursing care without excluding family cultural values. So, nurses and medical personnel can also provide comprehensive nursing care by paying attention to local wisdom. Likewise some researchers in several previous studies confirmed that the way of life embraced by families with autistic children influences the way families accept the fact that their children suffer from autism, make decisions and look for cure.^{11,12}

II. OBJECTIVES

The purpose of this study was to describe and explore family management of autistic children in ethnic Malay families.

III. METHODOLOGY

This ethnographic study was conducted on ethnic Malay families who have autistic children. The site of study was in Pontianak, the capital city of West Kalimantan, Indonesia. The families came from a nuclear family, an extended family, a single mother and an autistic child who lived with grandparents. Meanwhile, the purposive sampling method was used to determine key informants consisting of 20 ethnic Malay families consisting of 19 mothers, 16 fathers, 5 grandparents, 7 grandmothers. The process of collecting data from key informants took approximately 12 months starting from July 15, 2017 to June 15, 2018.

Prior to collecting data, the researcher submitted a research proposal to the ethical committee at Khon Kaen University for approval. Once the researcher obtained approval from the ethics committee, the researcher then sent an official permission letter to the research arrangement authority. The purpose of this letter was to request a permission of data collection. This study has been granted an ethic agreement issued by Institutional Review Board (IRB) of Khon Kaen University number HE602175, Thailand on 11th of July 2017.

The next stage was to enter the research setting and getting personal contacts of relevant persons or gatekeepers in order to get access to the field work. In the first month after obtaining initial contact with relevant or key persons, the

researcher conducted a "grand tour" on the family setting, autistic center, mental health hospital, and autism therapist center, and special education school.

The researcher prepared a list of some questions related to what the researchers were going to observe, and how to identify parents or families who have children with autism who live together. The purpose of the "grand tour" was carried out in the family and outside the family to identify potential key informants who were then selected to be participants in the FGD and in-depth interviews. The researcher took the role as participant observation. During the observations, the researcher took field notes which are the descriptions of events and behaviors frequency shown in the field work.

In order to obtain data accuracy, the researcher carried out weekly observations during 6 consecutive days. Which was conducted from Monday to Saturday for two to three months of study. However, it was also carried out on Sundays which was adapted to the key informants' free time at home. Next step after identifying and determining the key informants, the researcher sought the consent of the participants to voluntarily take a part in this study. Once they agreed to participate in this study, the researcher then explained the aims, process and procedure of collecting data as well as their rights as participants in this study. Provided with some explanation the participants then were required to sign form the informed consent as a statement that they have received all information and are ready to take a part as participants in this study.

As subsequence of conducting observations through the grand tour activities on research setting, the researcher conducted focused group discussion (FGD). The FGD was conducted as a part of data collection process. In the FGD the researcher first of all selected and identified the key informants to become participants in the in-depth interview. Interviews with key informants using interview guideline was carried out for around 45-60 minutes. In this process the researcher took field notes and audio recordings using a tape recorder to help record conversations during the interview process and the process of conversation transcription in the analysis process.

During the in-depth interview the researcher made field notes and transcribed each conversation. After the process the researcher then consulted with an advisor to get feedback and suggestion regarding the further steps to take in supporting the analysis process. Importantly to note that during conducting the research, although the researcher was directly involved in the participant observation activities, naturalness in this process was maintained to avoid bias. Therefore, the researcher took a role as an insider while in the same time remaining as an outsider.

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) How do you handle your child everyday, 2) How do you give everyday care for your child who has autism? 3) What do you do with your child at home? 4) What kind of activities do you do on daily life? And 5) What did you do once you discovered that your child experience autism?

Data was analysed using thematic analysis technique. First the researcher transcribed all the results of interview and focus group discussion then coding the texts line-by-line. As the coding results were generated, the researcher then looked in and determined themes based on the coding category determined previously. The themes were then classified according to categories that originate from each group of the codes. At the last stage the researcher wrote all the research findings. All phases of the data analysis were manually processed using Microsoft Word documents.

IV. RESULTS

This study found three themes about the family management of autistic children in Malay families, the three themes include 1) women act as main caregiver, 2) men manage autistic children, and 3) family seeking help.

Theme 1: Women acts as a main caregiver

In family with autistic child, Unlike male family members, women appear to have the biggest obligation regarding caring for an autistic child in their family. Culturally, an adult male in a family is responsible for fulfilling the family needs, a breadwinner and the one to make money.

The themes for women acting as primary caregivers consists of five sub themes as follows: 1) close supervision, 2) helping basic self care activity, 3) being locked to protect the autistic children, 4) handing the autistic child to a babysitter, and 5) avoiding particular foods. In the following each of the five sub-themes is explained one by one:

Sub theme 1: Close supervision

All autistic children in the home were closely monitored by main caregivers who come from the nuclear family, extended family, and single mother. Mothers took their children with them if they traveled or left home. Mothers apparently do not want to leave their children without their supervision. It is because there is a feeling of worry from the mothers if something not desired happens to their own children when left at home, like what was expressed by the following mother:

“He (autistic child) is never left alone, when at home I always watch him out, I am afraid if he might play with dangerous toys that can endanger him because he still does not know yet whether the thing is dangerous or not. I am also afraid of him throwing things around at home. He once left him alone at house even though I had just stayed outside for a minute.” (M7 aged 42 years old, autistic child aged 15 years old)

Sub theme 2: Helping basic self care activity

Most of women of those four types of family with autistic children helped their children to carry out their daily activity care. Mothers assisted their autistic children to either partially or totally execute their such basic needs activities as bathing, eating, putting on clothes, and other self-cleaning activities. In this case, the care provided by family members to children varies from child to child and at different levels. Some help

their children directly. This statement can be seen in the extract of the following interview:

“Of course, Sir. All activities need to help for example when eating he still needs to be fed, especially when releasing himself and urinating, well I don’t know what to say about that. We still need to bathe him too as well as when sleeping he still needs to be swung. Overall, it’s so hard for us, Sir” (Her face-expression changed.) (M2 aged 44 years old, autistic child aged 14 years old)

In addition to mothers who helped their children to meet their basic daily needs, other family members such as grandmothers also helped meet the basic needs of their autistic grandchildren such as bathing and dressing. Thoug, some grandmothers did not need to do all things for their autistic grandchild because some children have been able to do their own personal care. This can be seen from the expression of a 56-year-old grandmother who has a 15-year-old grandson with autism as follows:

“I have intentionally taught my grandson (autistic child) to carry out daily activity cares so that in the future he can do what he needs to fulfill his daily activity care. So, he will not rely on me, as you can see, I am already old. So, when he is bathing, I only help take out his clothes from the closet and give the clothes to him, subsequently he puts on himself. He can also eat alone, I only take rice for him because the rice cooker is hot when opened. I only need to watch him and remind him to wash his hands before eating. Well, that’s all, Sir” (GM4 aged 56 years old, her autistic grandson is aged 15 years old).

Sub theme 3: Being locked to protect their autistic children

A wide range of families with autistic children consistently appear to be aware to maintain the entryways of their homes closed. The family does this to make it simpler for them to screen their children and counteract them from going outside. The autistic children are not allowed to go outside of house unless they are accompanied by their siblings or other family members. Parents were anxious if their home doors are open they might lost control of their children's movement as they might get access to leave the safe spaces in their home. They are afraid if this circumstance may jeopardize their autistic children in case of a mishap. For instances, falling down, having an accident because of busy traffic passing in front of their house. Not to mention, there is a risk that children can disappear or get lost when they play alone outside, as expressed by several members of the nuclear family, extended family, and families with single mother as follows:

“When we have been home, I closed the doors at home and locked them to be safe, I also feel comfortable doing work at home, cooking, washing, cleaning, etc. If not, he may play outside the house, and it is so bothering to control him playing everywhere, but if he just stays inside the home, I will feel calmer and I won’t be worried,

Sir" (GM4 aged 56 years old, autistic child aged 15 years old).

Sub theme 4: Handing the child's care to the babysitter

Some working parents choose to use a babysitter's services to help care for their children. In this study, there are two types of family who employed a babysitter to help look after their autistic children. One is from the nuclear family background whose both husband and wife are working so that they can earn big income. The other is from a family background of a single mother who works and has no one to look after her child while she is at work. So, she must use the service of a babysitter, as revealed by these following few mothers:

"When I am at work, I leave my daughter with a baby sitter at home, Sir. The a baby sitter also accompanies her wherever we go, so that there is someone who helps me to watch my daughter. I feel that the babysitter is so helpful even though my daughter now is 14 years old, I keep the nanny with us in order to ease my housework as well" (M3 aged 32 years old, autistic child 13 years old)

Sub theme 5: Avoiding of particular foods

Some mothers based on the suggestion of therapists avoid giving their children particular foods such as chocolate and instant noodles. According to the mothers, if the children consume particular type of foods like chocolate or instant noodle, there will be an impact on the children's behavior. The children tend to be hyperactive and like to throw tantrums. While, the types and characteristics of families that control their children's foods, that is avoiding certain types of foods, are the families from both nuclear and extended families background whose main caregivers, mother, have undergraduate education background, as explained by some mothers as follows:

"I try to set his diet when he is eating, I do not let him eating chocolate, noodle, and other foods containing MSG, so I avoid those all" (M8 aged 37 years old, autistic child aged 8 years old)

Theme 2: Men manage autistic children in their family

Unlike mothers, in managing their children, fathers usually do it after returning home from work or on their days off. This is because fathers need to work from the morning time until the evening. Husbands who are willing to help their wife are those who come from both nuclear and extended family. Accordingly, there are various ways fathers do in dealing or managing their children when they are at home like inviting them to do exercise, teaching their children, and buying toys and foods for them. Theme the Men manage autistic children consist of one sub-theme, that is support the wife. In the following each sub-theme is explained one by one:

Sub theme 1: Support the wife

The main caregivers have the most support in raising children from their husbands of partners compared to other

family members. Support from partners can be in various ways such as accompanying their wives when checking their children to the doctor and soothing the spouse when she feels emotional and stressed out, and providing advice to remain patient in caring for their autistic children. This is done by husbands who come from extended family. While, helping and looking after their autistic children at home are usually done by husbands who are already retired. This involvement is also taken by husbands whose job is unfixed of freelance jobs who come from nuclear family background, as the following fathers say:

"Unlike other families, we cannot afford a housemaid, we even can only fulfill our needs and monthly therapy. So, to care for our children (autism) I am committed to helping my wife, we together, who can take care of our child. If she is tired and my wife is taking a rest, I am the one who is looking after our child. I accompany our child watching TV. And vice versa, if I am working, my wife takes care of our child at home. I pity her if everything is burdened to her, she can be stressed out. Especially taking care of such child, it is definitely hard for her if doing it alone" (F10 aged 34 years old, with autistic child aged 6 years old).

Father's attitude in sharing tasks and burdens with their wives in caring for their autistic children both emotionally and materially, as supported by the following mother's statement:

"My husband is a patient person, he who always strengthens me gives me enthusiasm so that I'm not overly sad, he is also the one who always helps me make milk bottles when my child is still small until now he also wants to help me taking the children to and from school if he is not busy. He is so kind anyway" (M14 aged 38 years old, autistic child aged 12 years old)

As for single mother families who been divorced from their spouse, some ex-husbands also still provides financial support for the care and living expenses of his child, as the following mothers say:

"My ex-husband sometimes gives a monthly allowance for my child's needs, it is usually about 2 million a month to pay the nanny, therapy and school needs. However, it is not enough. Thankfully, I also work, not only hoping for help from my ex-husband" (M3 aged 32 years old, autistic child aged 13 years old)

The forms of husband's support for their partners vary, from inviting children to play to just doing activities together such as teaching children at home when fathers have free time, as revealed by these following fathers:

"Taking care of this son I treat him just like my friend so that our relationship is not like a daddy and a son, but as friends. I try to do so. In the afternoon I sometimes take him along to play football in front our house. And

sometimes, on Sundays as a family we go for exercise together utilizing the moment of car free day at the city Sport Building” (F12 aged 42 years old, autistic child 17 years old).

In addition, some fathers who work as teachers, choose to teach their children to read and write at home to fill their free time, as stated by a father in this following extract:

“I teach him how to read, write, and draw. For school’s lessons, I teach him again at home to review what he got from the school. The point here is repetition, and if there is homework. I prepared a small whiteboard at home and bought some alphabet toys. I introduce him the alphabets one by one and I arrange into words so that he can easily understand them” (F9 aged 48 years old, autistic child aged 10 year old).

Theme 3: family seeking help

Having a child who is different from other children makes parents try to find treatment help to overcome and cure their child’s condition. All four types of families in this study searched for helps in different ways. Various types of treatments are carried out by parents ranging from traditional healing to visiting shamans or traditional healer. Generally, the characteristics of families who visited shamans are from single mothers and families with middle to lower income or those who have only high school education background or lower. Also, spiritual healing by visiting religious teachers or Uztad who can cure various diseases. Family taking their child to Uztad was the type of nuclear family and extended family who believed in their child to be disturbed by a genie.

The theme of seeking help consists of 3 sub themes such as: 1) traditional healing, 2) spiritual healing, and 3) medical treatment

Sub theme 1: Traditional Healing

Before visiting a medical doctor, some families with autistic children first of all seek for alternative treatment by visiting a shaman or a traditional healer who they think can heal their child. They hope that by visiting the shaman, they might know the causes of their child’s illness, and ultimately cure their child. Parents take their children to the shaman based on the input from neighbors or other family members. It is because the family members consider that autistic children as children who are disturbed by ghosts, or spirits. So, they need to go to the shaman in order for the shaman to be able to expel the spirits in the child’s body. At the shaman. the child is treated by giving the child a glass of plain water which was recited a mantra. The child was also bathed in flowers water, having his or her tongue rubbed or scratched with a piece of cloth or a ring. The types of families who sought help from traditional healers are single mother families, nuclear families and extended families who have average income from the middle to lower, like the following several key informants say:

“Before taking him to doctor, we took him to shaman because my parents said that such kind of child was

usually disturbed by spirits. My son was bathed by the shaman and his tongue was dredged up using a ring every morning” (M13 aged 39 years old, autistic child aged 10 years old)

In addition to bringing the child to the shaman, there are also parents who take their children to alternative therapy places such as Acupuncturist and body massage therapist. The hope of parents bringing their children to acupuncture and body massage therapists is that their children can talk and stop tantrums

“I took him to a massage therapist, Sir. Maybe, it was his nerve-clamped when he fell down. My son was given a massage therapy 3 times a week for about a month. But there was no change” (M8 aged 37 years old, autistic child aged 8 years old)

Sub theme 2: Spiritual Healing

Some nuclear and extended families brought their autistic children to undergo spiritual treatment. This treatment was carried out by an Islamic spiritual teacher known as *uztad*. Parents visit religious teachers in the Islamic boarding schools to seek for spiritual healing for their autistic children. However, some *uztad* are willing to be invited home. Parents bringing their children to the *uztad* expect for their children to recover from their illness. The Islamic therapy by an *uztad* is called *Ruqiyah*. In carrying out their therapy, the *uztad* implement Islamic spiritual concept and belief in a form of reciting quranic verses and prayer on a glass of water which then is given to the children. As recounted in these following conversations:

“Well, at that time, my husband and I took him to an Uztad for a healing. The Uztad said that my son was disturbed by a genie so that he likes to laugh by himself. My son then was given a glass of plain water which was read a prayer, and was given Ruqiyah (Islamic healing spells) by the uztad” (M7 aged 42 years old, autistic child aged 15 years old)

Sub theme 3: Medical treatment

The families coming from the three family types consist of nuclear family, extended family and single mother family felt that their efforts of providing their autistic children with various treatment efforts, both traditionally and spiritually, failed or unsuccessful, they brought their autistic children to seek for medical treatments by visiting a pediatrician and neurologist. They also did examinations at the hospital with medical doctors, in the hope that the parents know the diagnosis results and the exact causes of the problem experienced by their children so that their children could recover like other normal children. As mentioned by the following key informants:

“At that time our son was 3 years old, I took him to pediatrician as suggested by my husband. The pediatrician said my child has a problem with brain

development disorder resulting in speech difficulty as well as behavior problem, and the symptoms, according to the doctor, look like symptoms shown in children with autism. The doctor then suggested me to take my son to a child psychologist” (M13 aged 39 years old, autistic child aged 10 years old)

In addition, parents also brought their children to psychologists and physiotherapists. Parents took their children to psychologists on the advice of doctors who handled their children to overcome the problem of child behavior. While, parents consulted with physiotherapists to seek help to overcome the speech delay and misbehavior problems of their children, with the hope that children can communicate and have controlled behavior, like the following mothers' expressions:

“Once day, after meeting the pediatrician, I took him to a psychologist in the mental health hospital for a consultation. on the advice of a psychologist, I got my child undergoing speech therapy at a mental health hospital 3 times a week, every Monday, Wednesday and Friday” (M5 aged 29 years old, autistic child aged 7 years old)

V. DISCUSSIONS

Responsibility for managing children is not only the responsibility of a mother or woman, but every family member has their own part in managing the children. However, the results of this study found that women have a greater role in managing children at home while men are more likely to make a living or income to support his household needs. Generally, in Indonesia, views on gender roles between men and women cannot be separated from the cultural influences they adhere to. Especially, in Malay families between men and women sharing tasks in the household is a common thing. The wife is a housewife who is in charge of managing household affairs such as cooking, caring for children, doing housework.¹³ However, if the wife works, it is also not prohibited as long as she can manage the time between working and taking care of the household.

They also stated that a mother is the most important person and who acts as the primary caregiver in taking care of her child or children who suffer disability.¹⁴ Although mothers and fathers share a role in taking care of children with Autism Spectrum Disorder, still mothers have a bigger responsibility and a large part in caring and helping autistic children compared to fathers.^{15,16} This study results also indicate that families who have a large income will use the services of a house maid or a baby sitter to help manage their autistic children at home. The maid's presence is found helpful for mothers who work so that during they are at work, the management of their children at home is left to their maid or babysitter at home.

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 and colleagues regarding daily living skills in individuals with autism spectrum disorder. Their study findings show that the ability of autistic children to meet their daily needs is lower than those who are diagnosed with other non-spectrums.¹⁷ 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.

This study found that husbands in addition to working also act as providers of support for their partners in caring for children at home both financially and emotionally. For example, they accompany their wives to bring their children to therapy. In the same manner, grandmothers also take a part in providing care for her grandchildren who have autism. As an example a grandmother whose autistic grandson lives along with them because the child was left behind by his parents who remarried after they got divorce. As a result, it is his grandparents who provide support for the child, especially the grandmother who acts as the main caregiver for her grandson. The results of this study are in line with what Peterson's claim that families act as providers of support and provide resources for other family members in managing autistic children.¹⁸ Therefore, parents must be able to share their roles, duties and responsibilities in caring for their children. So, cooperation and sharing of tasks or roles in caring for children are needed, especially for children with special needs, who require special attention from both parents.

At the point when the autistic children spend time at home a mother or a grandmother constantly shut the entryways of the house. Especially when a mother or a grandmother cannot stay by her child due to doing house chores such as preparing for meals, taking shower, washing and doing house cleaning. While taking care of the family unit errands the mother or grandmother experienced trouble since they need to do multiple tasks while watching their autistic child. Subsequently, to assure that their autistic child was safe, the house doors were closed. If other family members, for example, kins and companions were at home, it was useful enough for the mother or grandmother as the essential parental figure to do the household errands. Correspondingly, Schaaf and colleagues found that families with mentally disorder children felt that they experience issues to complete their household errands and to all together take part in the family unit activity.⁸ Especially, in the morning activity families find the most difficult task to fulfill due to time constraints. As an example, when they need to prepare their children's needs and have breakfast together, they also need to get ready for work. Not to mention, afterward, taking their children to school on time. Therefore, the findings of this study confirm Schaaf et al. that to complete their homework assignments, parents

need to limit their autistic children's access to outdoor spaces.

In addition, parents also manage children by controlling the food consumed by children, the results of research showed that there are some particular foods that are restricted to a child with autism. A mother usually will monitor kinds of foods consumed by her autistic child. For example, an autistic child is banned to consume foods made from chocolate, noodle instant, and sausage. Mothers get worried if their children consume such kind of foods, their children cannot be controlled and will act hyperactive, throw tantrum, and talk alone. Therefore, mothers at home are very selective in terms of selecting foods for their autistic children and controlling which foods that are appropriate for the children with autism. Some autistic children are sensitive to some foods that contain particular additive substances. Especially the foods that contain gluten and casein, as found in a prominent study by Santahanam and Kendler claim that those substances may weaken immunity and cause metabolic disorder, nutritional deficiency as some foods may contain heavy metal toxicity, gluten and casein.¹⁹

Briefly, the researcher found that the first efforts a family carried out after they found out that their children have autism is going through both traditional and spiritual treatments, and then at the end they would seek for medical treatment method. Traditionally, a family visited a shaman, acupuncturist and body massage therapist. They also visited the Islamic spiritual healer. While medically, they visited specialist doctor, therapist in autistic center and mental health hospital. Traditional healing way is usually applied by a family that has a single mother family who has financial inability and low background education. This condition applies to both nuclear and extended family whose income is still low. It is because they believe that God will cure their children through *Ruqiyah*, *Uztad* intermediaries. In the end, medical care is carried out by all types of families such as nuclear families, extended families and single mothers after various treatment efforts. Therefore, the results of this study are in line with what was found by Riany and colleagues in their study on the efforts of families to seek treatment for children who have autism such as using herbs from traditional Javanese medicine, therapy using herbal medicines, and reflection massage from Chinese medicine.²⁰ Similarly, this study finding also confirm the benefit of some traditional and complementary therapies for autistic children implemented by some countries, for example Thai massage therapy. Thailand implemented Thai massage therapy as a complementary therapy that can help reduce emotional problems and attitudes in autistic children.²¹

Therefore, based on the results the researcher found and compared to the results of previous studies, massage therapy is one of the complementary therapies chosen by families in Indonesia and other countries. Considering Massage therapy can provide a feeling of comfort and relaxation for the limbs. Where this study found that in autistic children, massage is done on the face to stimulate blood circulation and nerves around the face so that stiff muscles can relax

VI. CONCLUSION

Families do various ways to manage their autistic children, and each family has its own way of dealing with their autistic children at home. In managing their autistic children, parents work together and share duties even though mothers seem to be the ones who have the biggest role in managing their autistic children at home. While husbands play a major role in making a living for their families. As for working mothers and families who come from middle to upper income families or have large incomes, such families usually hire domestic helpers or babysitters to care for their children rather than doing it themselves. Meanwhile for extended families, other family members such as grandparents and siblings, who live in the same house, are also involved in providing care for autistic children in their families.

Regarding child treatment, a family's effort and decision to obtain treatments for their autistic children would be mostly influenced by beliefs or culture to which the family adheres. Especially, for Malay families seeking treatment cannot be separated from the guidance of Islamic teachings. Thus, before their autistic children undergo medical treatment, the family will usually ask for advice from religious leaders, Islamic clerics, or *uztads* for consultation. So, the care given to their autistic children is adapted to Islamic beliefs such as healing with prayer, reciting the holy verses of the Qur'an, applying *ruqiyah* medical rituals and drinking water that has been prayed for by an *Uztad*.

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