

The life scenarios of family who have autistic child at home

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ABSTRACT

Living with autism is not easy for the autistic children themselves and their family members. Especially the family members who are also the main caregivers. This ethnographic study aimed to describe the ways of life of families who have children with autism at home. Data were collected through participant observations, focus group discussions and in-depth interviews. There were 20 families as key informants taken by purposive sampling who consist of mothers, grandmothers, and siblings. The data were analyzed by thematic analysis. There were four family life scenarios of family living with autism including: 1) basic selfcare activity, 2) locking doors to protect the autistic children, 3) woman act as a main caregiver, 4) risk of child abuse, and 5) supporting from spouse and other family members. Main care givers risk psychological, physical and social problems. Nurses should provide counseling to the main caregiver by deep listening to their concerns and teaching them how to manage stress. In addition, caregivers need supports from the family member particularly the husband.

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1. Introduction

Autism is a part of autism spectrum disorders (ASDs) which is categorized into a group of neurodevelopmental disorders and brain dysfunction. Autism is detected through symptoms categorized by core insufficiencies in three domains: social interaction, verbal communication, and repetitive or stereotypic behavior. The degree of impairment between individuals with ASD is variable, but the effect on affected individuals and their families is universally life-altering (Newschaffer et al., 2007; Lindgren & Doobay, 2011; CDC, 2016).

It is not easy for families to reside and live with autistic children. Family members are the first to feel the impact of having an autistic child at their home particularly parents who serve as the main caregivers are affected most because they not only spend the most time with their autistic children at home, but also interact and directly get involved in their children's every day life activity. Thus, parents experience various kinds of impacts and responses in caring for children at home both positive and negative impacts. The various emotional effects felt by the mother as the main caregivers such as feelings shocked, ashamed, confused, hopeless, afraid of having another child, worry about the future child, and being humiliated (Olson, 2010; Hartmann, 2012). The results of this study indicate that the first response given or shown by a mother once she knew that her child has autism was feeling shocked. Some mothers also experienced emotionally stressed out because of problems such as low socio-economic condition where the expense to be spent for her autistic child treatment is costly, and particularly for a single mother, she has to struggle alone providing therapy, school and

other needed attempts to cure her child. The mother also experienced easily short-tempered due to workload burden due to child's everyday self-care (Olson, 2010; Kusumawati, 2014).

Having a family member who has autism causes imbalances in the family system. The family must be able to adapt to changes that exist and get out of the pressures or problems generated by the situation. Family resilience illustrates how family abilities adapt to stress and bounces back from difficulties after being overtaken by misfortune or heavy pressure both from inside and outside the family, so that families become stronger and smarter in dealing with problems (Hawley & De Haan, 1996; Walsh, 1996). In this study, the status and situation of having an autistic child in a family become the factor derived from within the family itself that cause the family stressed out and have a potential to cause pressure and imbalance in the family system. As a result, violence appears to children carried out by parents or family members as a result of being unable to manage both physical and psychological stress. Therefore, supports from spouses and other family members are crucial in nurturing and caring for children with autism.

Thus, this study aimed to describe the family-life situation with their autistic children at home which consists of the interaction of autistic children with their parents and other family members.

2. Research Method

An ethnographic design was used in this study. The ethnography is a qualitative research methodology used to identify and understand the ways of life, interactions, beliefs, and perceptions of families with autistic children.

The key informants in this study consisted of 20 families consisting of 19 mothers, 3 siblings, 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. The key informants were selected using a purposive sampling method. This study was carried out in the family with autistic children in the city of Pontianak, the provincial capital of West Kalimantan, Indonesia.

The techniques used to collect the data in this study were participant observation, focus group discussion, and in-depth interview. In the initial data collection, the researcher conducted first observations at an autistic center and a local mental hospital in order to meet parents who have autistic children. The observations also aimed to see the activities of parents and therapists with the autistic children who were treated at the autistic center and hospital. Afterward, the researcher conducted home visits which were purported to observe family activities together with their autistic children at home. During the carrying out participant observation at home, the researcher conducted in-depth interviews with parents and other family members such as sibling and grandparents. In Focus 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 instruments used in conducting in-depth interviews was interview guidelines developed by the researcher based on the research objectives. Data were collected using both a tape recorder and field notes. The examples of main questions based on interview guidelines include 1) how do you help your child do the activities? 2) why you help your child do the activities? 3) what kind of activities did you do on daily life? 4) what do you need to care your child at home?

In analysing the data collected in this study the researcher used the thematic analysis technique. According to Braun and 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 last process is to write up. In the first stage the researcher 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 processes of stages in analysing the data were 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 on 11th of July 2017. Objectives and information regarding this study were explained by the researcher to each key informant in accordance with the available information sheet. The key informants who were willing to participate in this study, they signed the informed consent provided. As for children who are under 17 years old, parents were required to accompany them during the interviews and their parents who signed the informed consent. Key informants were also given freedom whenever they wanted, they could withdraw as participants in this study. Furthermore, identities of all informant keys were written using initials or codes. 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 the key informants.

3. Result

In the category of at home life-scenarios, there are five themes family life scenarios of family living with autism including: 1) basic self-care activity, 2) being locked to protect the autistic child, 3) woman act as a main caregiver, 4) risk of child abuse, and 5) supporting from spouse and other family members. In this following section, the researcher will explain one by one of the five themes of the lives of autistic children with their families, as follows:

3.1. Basic Self Care Activities

In fulfilling daily basic self-care at home, autistic children have not fully been able to do it by themselves. Some are totally dependent on family members's assistance. Some other have been able to carry out their daily basic self-care partially. Nevertheless, there few who have already been able to carry out such self-care independently. In this study there are three sub-themes of self-care activities that have been resulted. Sub-theme division is based on the level of dependence of each child on his family in terms of fulfilling the activities of daily life. Therefore, the three sub-themes consist of 1) autistic children need total care, 2) Autistic children need partially care and 3) fully independent. In the following part each of three sub-themes is explained one by one:

a) Autistic children need total care

There are 15 families whose autistic children still require full assistance to fulfil their daily activity cares. 7 children come from nuclear families, and 6 children are from extended families, while the other 2 children come from single mother families. Most autistic children are unable to independently perform everyday activities for their basic needs at home such as bathing, eating, dressing, and other personal hygiene activities as expressed by these two mothers as follows:

"Taking care of my child is like taking care of a baby, because I have to do everything for him like eating, I have to prepare food and feed him, and while taking a bath I still need to join him in the bathroom, I still have to bathe him" (M6 aged 34 years old, autistic child aged 6 years old).

Likewise, in the extended family type, there are 6 children who live within this family type who are still fully dependants to their family's help. Therefore, in order to meet their daily needs, parents and family members assist them with those tasks so that they can meet their basic needs. One of six autistic children in the extended family type in this study have a 12 - year-old. He still relies on his mother to fulfil his basic self-care needs such as bathing and putting clothe on, as illustrated by these following key informants as follows:

"Even he can't try to put on his own clothes and pants. You know, that a child who is already in grade 6, when taking a bath, he still needs my accompanion, or sometimes also with his mother. Even though I have taught him that, when we take a bath, I show him how

to wear his clothes on. But if I do not put clothes on him, still, he will not be dressed” (M14 aged 38 years old, autistic child aged 12 years old)

Not only children who come from nuclear and extended families who need totally daily activity care, but also some children who come from single mother family. For example there was one child classified in the category that needs totally daily activity care, He is 14-year-old autistic child who cannot carry out daily activity care independently and need totally dependent on family members. Regardless of his age that has entered adolescence he still need assistance from his family members in fulfilling his daily activity cares such as eating, bathing, and cleaning or washing after urinating or defecating, as expressed by sibling as follows:

“... My little brother (sibling) frequently pees and defecates carelessly, and he (autistic child) doesn't tell us when he needs to release himself. So, after he defecates, I clean him. Then in the afternoon I also bathe him, I usually would take turn with my mother for taking care of him, I would feed him, help him wearing clothes. Well, we do anything he needs for him because he does not know anything about how to take care of himself (Sibling aged 18 years old, autistic child 14 years old)

b) Autistic children need partial care

On the other hand, there are 4 autistic children who have been capable to partially carry out their daily activity cares. Two children aged 15 and 17 respectively come from nuclear families. Another 16-year-old female autistic child comes from a single mother family, and the other is a 15-year-old boy who lives with his grandmother. These autistic teenagers have been able to carry out daily activities such as eating and bathing themselves. Their parents only need to remind them when the time to do the activity comes and monitor them while doing activities as articulated by mother who has autistic child as follows:

“My child (autistic child) can eat alone, take a bath alone, but sometimes if he (autistic child) bathes himself, it is not clean. There is still soap sticking to his body. So, I invite him to go back to the bathroom. I help flush his body again until his body gets clean. Then I remind him to dry his body and wear his new pants and clothes. As soon as he is ready with these steps, he can then get out of the bathroom, otherwise he usually likes to come out of the bathroom with the body still wet, and forgive my words, he didn't wear pants” (M20 aged 51 years old, autistic child aged 17 years old)

Similarly, the autistic 16-year-old girl of single mother family is also almost independent in carrying out her daily activity care. Her mother has taught and trained her to carry out the daily activity care and supervises her when she is doing the activities as said by his mother (autistic mother) as follows:

“I (mother) am so grateful that my child can independently bathe, eat, drink, dress, and comb her own hair. I just need to remind her. For example, I instruct or remind her about bathing, and eating. I also watch her when she (autistic child) wears her clothes in case she wears them upside down. However, there is still one task that she has not been able to carry out it on her own, that is putting up the sanitary napkins when she has her period. For this task, I am still teaching and helping her how to do it... (M1 aged 58 years old, autistic child aged 16 years old)

Likewise, an autistic child who lives with his grandmother, his grandmother has taught her grandchild to do daily activities care so that in the future can be independent considering at the moment the child is living with his elderly grandparents, as expressed by his grandmother in the following transcript:

“...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)

c) Fully independent in daily activity care

Of the 20 families, there is only one family who has autistic child who is able to be independent in carrying out his daily activity cares. This 17-year-old boy comes from a nuclear family. He has undergone therapy since the age of 3. He was also trained by his parents at the age of 5 and has become independent when he reached the age of 10. Mother of this autistic child is a teacher who is also a therapist for children with autism. So, she has better knowledge about how to teach her child to carry out his daily basic self-care, as recounted by his mother in this following transcript:

"...so, little by little I let him do it alone while observing him but now he, as you can see, can do anything. He even sometimes helps his father wash motorcycle and car even though we do not ask him to do so" (M12 aged 39 years old, autistic child aged 17 years old)

3.2. Being locked to protect the autistic children

The second theme for the category of home life scenarios is children being locked to protect autistic children. All type families with autistic children seem to always have their house door locked or closed. Families do this in order to ease them to watch their children and to prevent. Parents worry that when their door is open their children will come out of their homes. They believe that this situation endangers their autistic children in the event of an accident as expressed by one of key informant as follows:

"I (mother) locked the door so that he (autistic child) cannot go outside the house. It will be trouble if he goes out as he will wander anywhere. The safest way is just to lock the door and take off the key so that he cannot open it. If I take him out, I must be always by his side, and I always hold his hand" (M17 aged 37 years old, autistic child aged 3 years old)

3.3. Woman Act As Primary Caregiver

The all family types with autistic children, a mother seems to have the greatest responsibility for caring her autistic child when compared to a father. As for nuclear family, if a mother does not work it is the mother alone who will be responsible for her autistic child care and sometimes assisted by the child's siblings, especially when they have free time as revealed by some mothers who come from nuclear family as follows:

"... I (mother) bathe him (autistic child), prepare him (autistic child) food, feed him (autistic child), help him to put clothes on, take him (autistic child) to school and therapy. I don't have an assistant. So, from morning to night time my child (autistic child) has more time with me (mother), while my husband is at work from morning until afternoon" (M15 aged 34 years old, autistic child aged 7 years old).

However, different from extended family, a mother who acts as the main caregiver to the autistic child sometimes involves other family members in providing care for the child, for example a grand mother who lives along with the child within a family as stated by some mothers who have autistic children as follows:

"When at home early in the morning, I (grandmother) usually bathe my grandson (autistic child) as his mom has already left for school at 6:30 a.m. Once my grandson wakes up at 8, I bathe him straightaway. After that I buy porridge at the corner food shop and feed him for breakfast. Usually, when I am feeding him, I take him to sit along in our house terrace while observing other children playing in our neighborhood" (GM16 aged 60 years old, the autistic grandchild is 4 years old).

Unlike the condition of other single mother with autistic children, she taught and trained her daughter to carry out daily basic self-care and do them together. She also takes her daughter along when she goes to work as a laundry worker at the neighborhood. In the following conversation script, a piece of dialogue spoken single mother is as follows:

"...Once we are home from work I have a lot of time with my daughter at home I teach her to read, so he knows the letters and numbers. Then I also teach her to wash her clothes, sweep and mop the floor with showing an example to her, I do not want to later after I am died, she could not know how to do house chores and take care of herself (crying)"(M1 aged 58 years old, autistic child aged 16 years old)

As for the autistic children who live with their grandparents, grandmother is a primary caregiver for her grandchildren. In providing care for her grandchild, a grandmother mostly carries out only a part of the activities and assists her grandchild to do particular activities such as helping prepare clothes, taking rice from a rice cooker, like the following grandmother's expression:

"If not me, who else will look after him. The good thing is that he has been already able to do some basic needs like eating by himself and taking a bath by himself. I only need to prepare meal for him, and prepare the clothes for him to wear and checking him putting his clothes on, and for school, I also deliver him to school" (GM4 aged 56 years old, her autistic grandson is aged 15 years old)

3.4. Risk of Child Abuse

Autistic children are at risk of getting abuse from their families. The types of family that are at risk of doing abuse to autistic children are families comprised a single mother and grandparents who live with an autistic child. The kind of physical abuse comprises being beaten or pinched by his own mother. The following interview is one example of how a mother from a single mother family treats their autistic children as follows:

"Sometimes I (mother) pinch my son's ears if he behaves too far. He (autistic child) usually likes to fight for TV channels with his little brother, and none of them wanted to lose. So, I pull AM's (autistic child) hand and I separate him from his little brother. I then command him to get into his room, and I let him cry and scream out loud in his room until he gets quiet by himself" (M2 aged 44 years old, autistic child aged 14 years old)

In another case, an autistic child who lives alone with his grandparents seems to burden his 56-year-old grandmother. In this case, the grandmother admitted that taking care of her grandson very tiring and overwhelming because there was no one that helps her to look after the child, when at home as expressed by a grandmother in this following conversation excerpt:

"... It's very difficult to take a nap when having a grandchild like that. While his parents, each enjoys her and his own new married life, and they left their son with me. So, when I (grandmother) get angry, I pinch him and hit him, sir. Well, I'm also an ordinary person, sometimes my patience also has a limit when dealing with a grandchild like this" (GM4 aged 56, the autistic grandchild is 15 years old)

3.5. Supporting From Spouse

The fifth theme of category of life scenarios at home is supporting from spouse. There are 3 nuclear families with autistic children whose spouse also gets involved in taking care of their autistic children. They (husband and wife) together taught their child to study at home, who happens to be both parent and also teacher, as said by the following key informants:

"Both me and my spouse are teachers, so usually, when we arrive home from teaching at school, at night my wife or I assist our son to do his homework or just to teach him how to read and count or how to do homework from school. So, we always do such activities to our son" (F5 aged 30 years old, Autistic child aged 7 years old)

4. Discussion

The findings in this study reveal that most autistic children need total help from families, particularly from the main caregivers. Ideally children aged 13 to 17 should have been able to meet their own needs such as eating, bathing, dressing, and cleaning themselves at the time of elimination. However, the autistic condition of the children requires them to depend on others in meeting their needs. The children's age also plays a vital role in ASD children's ability to meet their self-care activities and physical cares along with their parents (Gorsky, 2014). In addition, the level of autism disorders experienced by children determines the ability of children to meet their basic needs particularly when the level of the disorder is categorized as severe autism, it will be difficult for children to carry out basic daily activities independently. The results of previous studies conducted by Dudley & Emery (2014) in autistic adults have shown that adults with autism still need help in carrying out daily activities such as defecation, bathing and wearing clothes. Dudley and Emery's study finding was supported by Gorsky (2014) explaining 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 (Bal et al., 2016). 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 condition is affected by neurodevelopmental impaired and severity Autism Spectrum Disorders symptoms experienced by children.

When the autistic children at home the doors of the house were always locked by their mother and grandmother. It is because the mother or grandmother could not be by their children side all the time particularly when the mother or grandmother did their house chores such as cooking, washing, and did cleaning house, and taking a bath. Sometimes, in handling the household chores the mother or grandmother experienced difficulty because they have to pay extra attention when monitor their autistic children inside home. Therefore, to provide a sense of security for their autistic children when they were not there because of their other household chores, locking the house door was the only option however, if their other family members such as siblings and spouses were at home, it was helpful enough for the mother or grandmother as the primary caregiver to do other household chores. Schaaf et al, (2011) through interviews in their study found that families with autistic children felt that they have difficulty to finish activities in carrying household tasks as well as to together participate in the household activity. For example, families felt that family morning activities is the most difficult tasks to meet due to time constraining since parents need to leave for work o time. Meanwhile in the same time they have to first of all prepare basic needs of their children, and afterwards they have to take their children to school on time. Furthermore, Schaaf et al. believe that in order to be able to complete their household tasks, parents need to limit their children's access to house doors so that they can keep their children to remain in the same space with them all the time.

Women who act as the first caregivers for autistic children comprise mother who have autistic children, grandmothers who look after their autistic grandchildren and female siblings who have siblings with autism look after their autistic siblings after doing their own activity such as school. Women act as the primary caregivers for autistic children in their family because as a mother, for example, a woman has a big responsibility in rearing her children, taking care of her household, but in the same time she also needs to work to support her family. On the other hand, male family members (i.e., a father and a grandfather) have role as a bread-winner and are responsible for making money to support their family as well as their autistic children's treatment. The finding of this study are affirmed by some researchers like Sharma et al (2016) claiming that women are the most important person and who acts as the primary caregiver in taking care people who suffer mental illness. Similarly with Gray (2003) found that mothers and fathers share a role in taking care of children with Autism Spectrum Disorder but still mothers have a bigger responsibility and a large part in caring and helping autistic children compared to fathers. In short, a father is usually a breadwinner who is responsible mostly for earning money in order to fulfill the needs of his family. Whereas, a mother takes care of all care needed in the household especially, taking care of her autistic child ranging from physical needs like eating, cleaning, and affection (Maulana, 2015).

Autistic children are at risk of getting child abuse from the primary caregiver such as from their mother or grandmother. This finding was supported by Gray (2003), he has reported that women are more vulnerable suffering stress than men in caring children with autism. This has been affirmed previously in some studies' findings saying that being the only person who is in charge in taking care of a child with disability risks the mother of being violent or negative to her child. The burden of responsibility can lead the single mother to stress because she feels alone and has to take care of all needs, both breadwinner and lone caregiver, which were supposed to be covered by a married couple in her family, and she is the only one who accepts negative attitudes or views from other surrounding people regarding her child (Koydemir & Tosun, 2009; Kusumastuti, 2014).

Spousal support is very crucial in rearing children with autism since mother as the primary caregiver will feel helped and her work will be lighter. The aid given by a husband can reduce the stress faced by the mother since she will not feel alone in taking care of their autistic child and she can be stronger psychologically. Moreover, spousal support has led to a good relationship between a husband and a wife in maintaining marriage and caring for children who have autism. This notion confirms the study by Hoffman (2012) revealed there are various ways of couples support each other, including 1) sharing responsibility for caring the children with autism at home, 2) giving couples a free time to rest because couples realize that caring for children with autism is a big challenge so couples must be given free time to rest, and a husband or wife can take turns alternately so that the

stressor decreases. In Indonesia, the views on gender roles between men and women are inseparable from the cultural influences they hold. For example in Malay culture, there is an equal role of a man and a woman. It can be seen from the how both genders share duties regarding responsibility of household matter. It is also shown through the contribution of women in various fields in government as well as private institutions. Basically, they are only partitioned or separated based on their respective natures. Not to mention, Malay culture believe that women are highly respected and glorified as taught in Islamic teaching to which they adhere most (Agustiar, 2004).

5. Conclusion

The children with autism who are indeed living within their family influenced other family members such as mother, father, siblings and grandparents. If the family is not able to maintain the balance both physically and psychologically due to having family member who has autism the condition will affect the health of other family members. Nurses should provide counseling to the main caregiver by deep listening to their concerns and teaching them how to manage stress. In addition, caregivers need supports from the family member especially the husband.

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