

Impacts of having Children with Autism in Malay Family of Indonesia

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ABSTRACT

Background: Having an autistic child and living together may not be easy for the affected families. The families may experience and face various effects when caring for their autistic children, both physically and psychologically. This study aimed to describe the impacts of having children with autism experienced by Malay family in West Kalimantan Indonesia.

Methods: This ethnography study employed participant observations, focus group discussions, and in-depth interviews to gather the data from 20 Malay families who have autistic children who were selected using a purposive sampling technique. The families served as the key informants comprising fathers, mothers, siblings, grandmothers, and grandfathers. The data collected through the three techniques were then analyzed using thematic analysis.

Results: The findings of this study generated five impacts categorized into themes consisting of (1) stress on main caregivers; (2) financial problem; (3) impact on employment; (4) impact on family or marital relationship; and (5) positive impact of having autistic children.

Conclusions: Families with autistic children have a high risk of experiencing physical, psychological, and social problems. Thus, to improve the quality of family health, nurses, and health workers need to teach the family how to manage stress properly. They may also need to provide counseling to primary caregivers by making a deep hearing of their concerns.

Key words: Autistic children, Impact, Malay family

BACKGROUND

Autism is a part of autism spectrum disorders (ASDs) which is categorized into a group of neurodevelopmental disorder 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.^[1-3] Therefore, in terms of family acceptance, at first, it is not easy for families to accept the reality that they have offspring who suffers from autism. They may react in different ways when at the 1st time they find out that one of their family members has autism until they have enough courage and ability to accept that situation. To put it in different way, having children with autism do not only impact the family in emotional and physical aspects but also in other aspects such as financial, work, and family relationship. Meaning, an autism diagnosis may change the family life

and give some impacts for the family, both in a negative and positive way.

According to Oslon, finding out that their children are diagnosed with autism for the first-time parents' first responses may feel shocked, denial, guilty, angry, and depressed.^[4] The same results from a study by Koydemir and Tosun confirm that there are four first-time responses from especially mothers when they heard their children have autism such as shock, depression, self-blaming, and rejection.^[5] Similarly, Ryan affirms that parents who have children with autism tend to experience some emotional problems such as feelings of sadness, rejection, anger, guilt, depression, isolation, stress, and financial difficulties, and struggles in marriage.^[6] In addition, Bromley *et al.* believe that parents who have children with autism are more likely to experience serious psychological distress than do parents whose children have other developmental disabilities.^[7] Parents respond that way because their children have special needs and are not like what they expect. In this case, it is not

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only parents who are directly affected by such situation, both siblings and grandparents are but also impacted in the same way, and both have unique approaches to respond to such situation.

Therefore, in addition to, the efforts made by parents in dealing with their autistic children, it seems important for nurses and health workers to understand the impacts of having autistic children for families. By knowing how the effects of having autistic children affect families, nurses, and health workers can provide and develop nursing and innovation interventions based on various cultural differences, values, and beliefs that exist in the community. Furthermore, they can also apply a cultural approach in the community when providing nursing care to individuals and families affected by the situation in accordance with the existing cultural background and beliefs. Thus, this study aimed to describe the impact of having autistic children in Malay families who come from Malay ethnicity background where they live according to the Malay cultural perspective.

METHODS

Design and Samples

This ethnography study was conducted in Pontianak City, West Kalimantan Province, Indonesia. The data were collected from the key informants from July 15, 2017, to June 15, 2018, through participant observations, focus group discussions (FGD), and in-depth interviews. The key informants involved in this study comprised 20 Malay families who have autistic children aged under 18. The key informants consisted of fathers, mothers, siblings, and grandparents who were chosen using a purposive sampling technique.

Data Collection

Three techniques used to collect the data in this study were participant observation, FGD, 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 and siblings of children with autism and also grandparents who have grandchild suffer from autism. In FGD the researcher divided the key informants into four discussion groups based on the level of education of the key informants. The father and mother groups of autistic children are divided into two groups. One group consisted of those who graduated from high school and the other group for those who have an undergraduate education background. While each of grandfathers and grandmothers had one FGD group, each FGD took place with duration of about 45–60 min and each FGD group consisted of six key informants.

Instruments

The instruments used in conducting in-depth interviews were interview guidelines developed by the researcher based on the research objectives. Several main questions asked in the interview include (1) what were the hardest feelings you experienced when living with your child who is diagnosed with autism? (2) How did you respond once you knew that your child has autism? (3) What are the impacts of having an autistic child in your family life?

Data analysis

In analyzing the data collected in this study, the researcher used the thematic analysis technique. According to Braun and Clarke

thematic analysis consists of six stages including transcribing all audio recorded an interview for verbatim data, coding, searching for themes, reviewing themes, defining and naming the themes, and the last process is writing up.^[8] 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) to ensure translation accuracy. The researcher re-read the translation results and made crosschecks so that the translation results are truly transcribed in accordance with what was 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 according to 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 findings. All process of stages in analyzing, the data were carried out manually in the form of a Microsoft Word document.

Ethical Considerations

This study has been granted an ethics agreement issued by Institutional Review Board of Khon Kaen University Thailand number HE602175 on July 11, 2017. The objectives and information regarding this study were explained by the researcher to each key informant in accordance with the available information sheet and for key informants who were willing to participate in this study. Afterward, they signed the informed consent provided.

RESULTS

In this study, the researcher found five themes of impacts of having autistic children on Malay family of Indonesia, the five themes include; (1) stress on main caregivers, (2) financial problem, (3) impact to job, (4) family relationship, and (5) positive impact of having of autistic children.

Theme 1: Stress on Main Caregivers

Having an autistic child may create a heavy responsibility for each mother. These study findings indicate that women mostly serve as the main caregivers who felt stressed out as they were given a huge responsibility in caring or looking after their autistic children. Besides, they need to care for their household and their whole family members such as children including their autistic child at home. It could be hard since the mother did not only care for the child's everyday basic self-care but also took the child to and from school and therapy center. Therefore, these daily chores activity impact the mother with autistic child both physically and emotionally. Thus, there are two sub-themes generated by the situation of a mother serves as the primary caregiver for her autistic child, such as (1) emotional problem and (2) physical problem. In this following part, the findings of this study are, furthermore, articulated.

Sub-theme 1: Emotional problems

Many emotional problems arose in main caregivers including shock when they first learned that their children were diagnosed with autism. They felt embarrassed to have autistic children, confused of how to care for children with autism. They also experienced hopelessness, fear of having another child,

worried about the future of children, and felt humiliated for having children with autism. These expressions correspond to expressions of some participants as follows:

"I was shocked, sir, when I first learned that my son was suffering from autism, I felt shocked or did not believe in what the psychologist explained. I thought it was too late, but after I took my child to a neurologist, the doctor also diagnosed my child has autism, I just never thought that the diagnosis to come out like that, sir" (M5 aged 29 years old, autistic child aged 7 years old).

An emotional problem like the shame of having an autistic child was also felt by other members of families with autistic children, besides father and mother. For example, as what was expressed by one participant in the following script:

"I was so ashamed to my neighbors and work colleagues especially they know if my husband has left me because I have a child with special needs. Maybe because he (her husband) was embarrassed too so that he... he... (her husband) left us. Our child indeed sometimes shows embarrassing behavior. Especially if there are neighbors or guests are visiting our house, he likes to laugh alone. Sometimes I ask my house helper to take him into the bedroom rather than disturb or make my guests uncomfortable later. I did not know what to do" (M3 aged 32 years old, autistic child 13 years old).

Having autistic children makes mothers feel confused in caring for and overcoming their children at home because their children like to behave strangely and are usually difficult to manage. This feeling of confusion is usually felt by mothers who have just had one child, as expressed in these following conversation scripts:

"In addition to feeling embarrassed, I was also confused about how to take care of my child every day. However, I, who interacted with him every day at home, feel the confusion myself. He does not want to obey what I tell him to do. However, he is afraid of the therapist and wants to obey him. Meanwhile, he is not afraid of me at all, when I forbid him from not doing inappropriate things, he will instead do the opposite even worse, like throwing things at me" (M6 aged 34 years old, autistic child aged 6 years old).

Parents feel hopeless because what happens to their children is not in line with their expectations. Especially, a father is the one, who feels hopeless the most, toward his male child who has autism. As parents expect a son will later become a household head, and continue the generation of the family in the future. As expressed by a father as follows:

"At first, I wished my son could become a mainstay in my family, considering I have only 2 children, a daughter and a son. My child who happens to have autism is my male child. So, what I hope is that he is able to go to college and could replace my position one day in earning money. As well as become the next generation of my family. And this hope immediately disappeared when I saw the development of my current son who is already 12 years old but could not communicate. He schools in SLB (extraordinary school). So, I have to give up that hope and accept the fact that my son has autism" (F14 aged 40 years old, autistic child aged 12 years old).

The feeling of the trauma of having an autistic child has a psychological impact on a mother with an autistic child to have

or plan to have the next child. There is a feeling of anxiety from the mother, if she plans to get pregnant again, in case she might give birth to an autistic child again. Some mothers delay another pregnancy even though their first child is over 6 years old, as the following mother says,

"I am not ready to get pregnant gain, besides wanting to focus on taking care of my son, I am afraid, what if the experience of my first son who suffers from autism also happens to my second child later. Thus, my husband and I decided to delay having another baby, but focus on taking care and looking after our first son" (M6 aged 34 years old, autistic child aged 6 years old).

Some mothers who come from a single mother family are worried about the future of their children. This is due to the condition of the children who cannot be independent and still need help from family members both in fulfilling the total daily activity care and partial daily activity care. As expressed by some mothers as follows:

"I worry about her future if I passed away, who will take care of her if I die later. Because we do not have anyone here (crying), she is my only child. I don't have family anymore, how can I not worry, Sir. Where will she live in the future and from where she will get foods. That's what I've been thinking about, Sir." (M1 aged 58 years old, autistic child aged 16 years old).

Parents feel that they are the topic of gossip or conversation of their relatives, neighbors, and coworkers at work. According to the parents, they become victims of bullying and jokes from their coworkers, such as making their children who suffer from autism as material or topic of conversation when they gather. They make the term autism as a joke in the room and even blatantly insult autistic children. As shared by this following key informant:

"Well, as usual, some people will talk about us for having an autistic child even though they said that they were only joking. They sometimes make a word "Autism" as a word used to tease each other. However, I do not care anymore about whatever other people say about my son. Bad or kind, he is my son. The most important thing is we continue doing our efforts to providing the best care for our son by taking him to therapy programs and fully giving our love and attention to him" (M10 aged 34 years old, autistic child aged 6 years old).

Sub-theme 2: Physical problems

Caring for autistic children physically affects mothers as primary caregivers either they are do not work or work, especially a mother who at the same time works while she is also responsible for the care of her children that is energy consuming. The example of physical impacts experienced by primary caregivers such as increased blood pressure, as revealed by the following key informants:

"Initially, I was so stressed out when taking care of him, at that time my blood pressure was getting higher around 160/100 when seeing his weird behavior, unlike other grandchildren" (GM4 aged 56 years old, aged 15 years old).

This impact also happens to grandmothers who help care for their grandchildren when their daughter is working or outside the home. Age affecting grandmother when caring for

her autistic grandchild for treatment activities will exhaust her easily and squeeze her energy, which affects her physically as expressed by the following 62-year-old grandmother, whose 14-year-old grandson has autism.

"I get headache, Sir. I have a hard time from dealing with him. You know, at home I am not only looking after of "AM (autistic child) alone, but also taking care of his little brother. When they fight with each other, I am the one who is busy to separate them. Sometimes, when I lose my temper, I beat "AM" so that he stops quarreling with his little brother. However, once I leave them to go to the kitchen, they fight with each other again. So, that's how it looks like when their mom leaves them with me at home."

Theme 2: Financial Problem

Having an autistic child requires a large amount of money for therapy and children's education. This is felt by parents who come from a family who are financially weak. The cost of therapy is great because it takes a long time to treat children with autism, as revealed by the following key informant:

"I have no fixed job so that my salary is also not fixed. I have 2 children, and to pay the expenses of my autistic son is sometimes hard enough to make, Sir. The therapy cost is expensive, I have to spend for almost one million per month. So, it is too much for me. As the result, my son can only undergo the therapy for 3 years in the private autism center, and 1 year free of charge in the governmental autism center. At the end, what we can afford is only taking him to school" (F7 aged 43 years old, autistic child 15 years old).

In addition, a single mother also had difficulty to meet the costs needed to care for her autistic child, as revealed by a 44-year-old single mother who has a 14-year-old autistic child as follows.

"I was confused thinking about cost, Sir....I work as a clothes launderer in some people's homes. My income will not be enough to pay my daughter's therapy and school tuition every month, at that time, the therapy was IDR 400 thousand and her school fee was IDR. 350 thousand. Where can I get such amount of money? sir. While in the same time, I also need to feed my family, and pay rent for the house. I don't have enough money to pay for everything. At the end, my daughter stopped undertaking both therapy and school."

Theme 3: Impact on Job

Having autistic children affects activities and how parents spare their time with their children. Some primary caregivers chose to resign from their jobs after they learned that their children had autism. Hence, they might be able to focus and care for their children at home, as revealed by one of the following key informants.

(Taking a deep breath) "I even resigned from my job when she was 3 years old because it is impossible to ask my mother-in-law to look after her so that I asked a permission from my husband, and Thank god my husband agreed with my decision to resign from work, for the sake of our daughter" (M18 aged 34 years old, autistic child aged 7 years old).

In addition, for children to go to school and get appropriate therapy, some families also decided to leave their previous jobs

and move to new areas and cities so that they could provide their children with therapy and school. Given that there were no facilities to deal with autistic children in their area before, as one key informant revealed as follows.

"My wife and I proposed job mutation to Pontianak, Sir. So that our child can be access a better handling. It is because in the region where we worked before, there have not been any autistic service centers. So, we sacrificed our job positions in the office and moved to new instances for the sake of our child" (F14 aged 40 years old, autistic child aged 12 years old).

Theme 4: Family Relationships

Having an autistic child has an impact on the mother, father, and all family members involved in caring for children. The impact occurs into the relationship between spouses who do not support each other causing a marital breakdown or even a divorce while the impact to other family members is a care responsibility conflict where the family members throw the care responsibility to each other. Conflicts also occur among siblings where other children might feel jealousy because their parents treat them differently from their autistic sibling in their family. In this regard, there are three sub-themes of the impact of having an autistic child in a family on the relationship among the family members such as (1) divorce, (2) family conflict, and (3) children feel jealous of their autistic sibling, as described below:

Sub-theme 1: Divorce

Having an autistic child has an impact on the husband and wife relationship because husband and wife are people who feel the most direct impact of having autistic children and those who interact with the children every day at home. Some wives, as the primary caregivers of the child at home, claimed to have an unharmonious relationship with their husbands. In some cases, after the husband found out that their child had autism, the husband filed for divorce and left his wife, as revealed by the following key informant:

"We had divorced since he knew that our daughter has special needs like this. But, he come once in a while to give money for my daughter's therapy" (Her tears came out from her eyes) (M3 aged 32 years old, autistic child 13 years old).

Sub-theme 2: Family conflict

All types of family experience conflicts in their family in caring for their autistic children. Conflicts occur between husband and wife who have autistic children due to the differences they have in terms of belief, view, or opinion in caring for and educating their autistic children, as revealed by key informants as follows:

"I told my wife to stop working to take care of my child but my wife did not want to, Sir, and still wanted to work because according to her looking for a job at this time is difficult. She also said that she can take care of the child after returning home from work. It is impossible for me as the head of the family to stop working then take care my child. It seems that my wife is more concerned about her work compared to the future of my child. So, when we work, we leave our children together with my mother-in-law at home, or my parents-in-law. I feel sorry for my mother-in-law, since she is already old and she complains while looking after our son" (F17 aged 37 years old, autistic child aged 3 years old).

In addition to the conflict between husband and wife, a conflict also occurs between parents of autistic children and other family members such as grandmothers of autistic children. This conflict occurred due to differences of opinion in the care of autistic children and differences in handling autistic children between parents of autistic children and grandparents of autistic children. Like the following expression:

"Sometimes I have a conflict with my mother in law, and sometimes I dispute with my mother in law because we have different styles of handling patterns. I understand, maybe in one side they have good intent for my daughter, but her grandparents often buy chocolates and snacks for my daughter" (M18 aged 34 years old, autistic child aged 7 years old).

Sub-theme 3: Feeling jealous of siblings

Parents treat their autistic child different from their other children that cause jealousy among them. In other words, parents give more attention to their autistic child when compared to the autistic child's siblings because parents realize that their autistic child needs special extra attention. Siblings who felt jealous of their autistic sibling for the different treatment they got from their parents are those whose age ranges from 9 to 12 years. Due to the fact that they also need affection from their parents, as revealed in these following transcripts:

"My big brother is more privileged by my Mom. If I am angry with my brother, surely my mother will be angry back with me. Even though sometimes my brother is wrong, but in my mom's eyes, my brother is always right, even though my brother likes to damage and scratch my school books" (S14 aged 9 years old, autistic child 12 years old).

Theme 5: Positive Impacts

Nonetheless, there are also positive impacts that arise after a family is aware of and able to accept the condition of their child having autism. Since all key informants are Muslims, they base their conditions on Islamic ideology so that they, on the one hand, get positive values from having autistic children in their families. In this situation, there are two sub-themes of the positive impacts of having autistic children such as (1) becoming a more religious person and (2) unconditional love as well as becoming more attentive to children who suffer from autism.

Sub-theme 1: Becoming a more religious person

For example, they become more religious in practicing their religious activities, as expressed by the 41-year-old mother who has a 4-year-old autistic child as follows.

"In the past I was not really sensitive when there was a beggar asking for money. Now, I spare 2.5% of my salary for donation in the mosque or poor people. By doing this, I hope God will show God's power to cure my son and make my prayers come true because my wish in making donations is for the sake of my son's recovery" (F16 aged 41 years old, autistic child aged 4 years old).

Sub-theme 2: Unconditional love

Another positive impact for families who have autistic children is that the families care of and love their children more. Accordingly, the families show their care and love for their autistic children in different ways. Some show their love by buying toys for their autistic children, taking them out for a walk or to the mall, buying the foods. Even there are some mothers who postpone

to have another baby so that they can spare a lot of time for their autistic children. It is because the parents are fully aware that their autistic children need more care from their parents. As expressed by these following key informants:

"Either Good or bad, she is my daughter, sir, if not me as her mother who else will love her and can accept her condition, I know very well how difficult I was when giving birth to him until I struggle to raise her until now. I have devoted my attention to her, I also postponed to have another child just to take care of her sir, as considering that she needs fully loved by us, her parents" (M18 aged 34 years old, autistic child aged 7 years old).

The same thing was said by a 30-year-old father who has a 7-year-old autistic child as follows.

"Because I love him so much, I will surely buy him whatever he wants or points at such as toys or foods I will give it to him, even my life. Before he goes to bed, I always hug him and kiss his cheeks. I sometimes cry when look at him as I feel so sorry for him, why has God given our family such kind of trial".

DISCUSSION

The purpose of this study was to identify the impacts of having an autistic child on the family. The findings of this study analysis generate five themes of the impacts of having an autistic child on the family, such as stress on the main caregivers, financial problem, impact to job, family relationship, and positive impact. The following is discussed each theme of impacts faced by parents from having autistic children in their family.

Stress on the Main Caregivers

The various emotional effects felt by mothers as the main caregivers such as feelings shocked, ashamed, confused, hopeless, afraid of having another child, worry about the future child, and being humiliated. This study results indicate that the first response given or shown by a mother once she knew that her child has autism was feeling shocked. The findings of this study confirm some of the results of previous studies, for example, the study of Olson which claims that parents' first response to hearing their children diagnosed with autism was feeling shocked, denial, guilty, angry, and depressed.^[4] Similarly, same results of another study found by Koydemir and Tosun confirm that there are four first-time responses of mothers when they heard their children have autism, the first is a shock, the second is rejection and depression, third is self-blame, and finally fourth is denial.^[5] Furthermore, according to Ryan, the sequential feelings experienced by parents once they knew that their child has autism.^[6] The parents showed a set of feelings such as the first feeling of sadness, next feelings of rejection, anger, and guilt, after that, they might feel depressed, and finally feeling of isolation.

In this study, the researcher also found that mothers were worried about their children's future. The results of this study assert the findings of previous research conducted by Baba that parents are afraid of the future of their autistic children.^[9] In addition, this study's findings are also reinforced by Greenberg *et al.* claiming that elderly parents who have autistic children are worried about the future of their children who experience disability.^[10] Thus, according to the researcher, this feeling arises because parents feel that no one will support their child when they are helpless due to age.

The results found by the researcher in this study confirm the results of previous studies conducted by other researchers on the same topic that claim the main caregivers felt more negative effects from having and caring for autistic children than positive effects. The researcher draws a conclusion that the negative impacts felt by the main caregivers seem to be the resulted from various factors such as no spousal support, lack family support, financial problems, bad stigma from the surrounding community, bullying, and overwhelming fatigue or exhaustion which lead to health and physical problems.

Physical Problems

Having an autistic child in a family impacts both inner family members, both psychologically and physically. The researcher found in this study that it is a mother or a grandmother, the primary caregiver, who experiences most physical impacts of dealing with an autistic child or children in her family. Some physical problems comprise fatigue, increased blood pressure, and weight loss, not to mention, anger, or temperamental behavior. On the same study, the topic also revealed that mothers feel exhausted caring for their autistic sons and daughters as they enter adolescence and adulthood.^[11] Physical fatigue triggers other health problems such as blood pressure, dizziness, and lack of appetite.^[12] Especially if this happens to mothers who are at their 40–59 who care for an autistic child, physical fatigue can cause diabetes, high blood pressure, high cholesterol, obesity, and arthritis.^[13]

According to the researcher, the physical impact that occurred on the main caregiver cannot be separated from several factors, such as the age of the caregiver. Especially the grandmothers who entered the elderly age so that the impact on physical fatigue when they have to supervise their grandchildren. Similarly, mothers whose role is as the caregiver, besides taking care of their household chores, they also have to care for their autistic children, for examples, looking after their children, taking them to and from school or therapy. As a result, those high maternal activities trigger physical fatigue and physical health problems such as diseases mentioned previously.

Financial Problem

Having an autistic child requires a large amount of money for therapy and children's education. The cost of therapy is great because it takes a long time to treat children with autism. Specifically, for therapy and education, parents need to spend around 1–2 million rupiah per month. However, for parents who come from disadvantaged families, it is so difficult. Especially for parents who do not have a fixed income source or low income. The results of previous studies found a situation that was not much different from what the researcher found in this study. The findings of this study indicate that some single mothers experience financial difficulties because they have to work alone, and it is very difficult to find extra money to support caring for their children who have autism. This condition affects single mothers physically and mentally.^[14] Large costs are needed because autistic children must undergo some special health care needs in several places.^[15,16] As a result of experiencing financial problems, families need additional income for the cost of medical care of their children who have autism.^[17]

Financial problems arise in families who have autistic children due to the high cost needed for treating autistic children.

Concerning that, the children do not only need to undergo one type of therapy but they also need to school. In addition, in many cases, one partner must reduce working hours or even quit a job because they have to take care and take time for children at home. Similarly, financial problem is also a risk factor that emerges physical problems due to parents' fatigue in seeking additional money and work, as well as psychological problems due to stress when thinking of costs for the needs of children and households. Not to mention, it also causes family relationship problems.

Impact on Job

As regarding the career affected by having children with autism, the researcher found in this study that women (mothers) are the party whose career is affected most. Most of the mothers decided to quit their jobs and focus alone on taking care of their autistic children and work only as of the housewife. She puts responding to her autistic child as the priority. Therefore, a mother pays her extra and intense attention to her autistic child such as giving her child more attention and affection and spending more time with the child, taking the child to therapy, waiting for the child during the school time, and helping the child to meet her/his basic daily needs. In addition, the mother quits her job, too, because there is no one else who could help her care for the child while working. Consequently, resigning from a job is one solution to take in that case.

This study agrees with the results of previous studies showing that having autistic children have changed the careers of several mothers, such as mothers choosing to quit their jobs even though the job was already established, some moms chose a part-time job or do online business, though some are still working as usual.^[18,19] In line with Matenge and Girli, Koydemir and Tosun, the impact of having autistic children on maternal careers includes career delays, stopping from work, and reducing working hours. On the other hand, for husbands, having autistic children, according to Olson's research will force them to work overtime or seek additional employment opportunities to earn extra money.

According to the researcher, some mothers resigned, but some chose to keep working, in that there are several factors that influence the decision. If a mother lives along with her parents, the mother will still choose to work because there is someone at home who can look after her child that is her mother (the child's grandmother). Meanwhile, families who come from middle up economic status seem to be able to employ a babysitter or a housemaid to look after their children when the parents work. Finally, having an autistic child certainly requires a large amount of money so that both husband and wife must work hard to get much money for therapeutic needs. In addition to having an impact on the career of the mother, this study also found an impact on the father of an autistic child. For example, as what was reported in this study, parents had to change jobs and moved out from their previous workplace located in a district-based region to the urban or big city so that they can provide therapy for their children where facilities for autistic children therapy are available.

The further impact experienced by a father for having an autistic child is that a father needs to work extra to meet his family's needs such as paying for school and therapy for his child and his household expenses. Although the researcher has

not found the negative impact of moving from former work from rural areas to urban areas, the results of the previous study by Frye indicate that some fathers work overtime and sacrifice their family quality time to earn extra money for school and therapy needs, as well as household needs.^[15] Still, according to this study, some fathers who have a personal business will work hard to earn and get revenue and take advantage as much as possible for the sake of their family's needs.

Family Relationship

In this study, there were three couples who got divorced when they found out that one of their children had autism. The reality of their children having autism is thought to be the main trigger factor for their divorce. It mostly husbands who left their wives and children and abandoned their children to live with their ex-wives, and even some husbands seemed to not care at all of their autistic children. The findings of the researcher also show that in addition to divorce, having autistic children also raises spousal problems such as disharmony between a husband and wife relation, such as disputes that occur due to differences of opinion in the term of caring autistic children.

Hence, this study result has a similar voice with some studies of other researchers about the spousal problem caused by having an autistic child in a family. The studies also revealed that having autistic children lead to divorce and low-quality relationships.^[5] According to Hartley *et al.*, the prevalence of divorce in families with autistic children was about 23.5% higher than divorce rates in families that do not have children with disabilities that were only 13.8%.^[20]

Having an autistic child raises the higher stress level than the parents who do not, so the parents need to communicate and share parenting with each other so that they both feel that they have children and similar responsibility. Not much different from what was conveyed by Miranda *et al.* that the cause of divorce in families with autistic children is a lack of emotional support from one partner, where one partner such as a wife is busy with parenting activities and handle autistic children so that one partner, a husband, feels ignored by his partner.^[21] Which seems that in those cases, a husband failed to understand and take a part in overcoming their autistic child's need and the struggle faced by their spouses.

The findings of the research showed that siblings showed feelings of jealousy toward their siblings who suffered from autism due to different treatment of parents. Besides jealousy, a sibling who is already teenager showed feelings of shame if their friends knew she had an autistic sister. In contrast to the previous findings, it also showed a positive sibling attitude that helped his parents look after his younger siblings when the parents were busy doing housework.

Some of the previous researchers also found several similar responses toward the children who have autistic siblings. Having an autistic sibling made a sibling's relation negative with their friends.^[22] Siblings felt shame toward the attitude of their autistic younger siblings.^[23] Based on the findings of bishop, the friends bullied the children who have an autistic sibling. Siblings also felt unfair treatment from their parents; however, the positive impact that appeared according to bishop, siblings showed their responsibility for the younger who is autistic by protecting, teaching, and nurturing them.^[24] According to researchers, the sibling's feeling, such as shame and different treatment

of parents, caused the jealousy that is influenced by the age of siblings who are still children and adolescents. They have not been able to fully understand the condition of their siblings who need special attention from the closest people including themselves. However, for siblings who are able to understand the condition of their siblings, they will show empathy by giving affection, playing together, helping to nurture, and even protecting their autistic siblings.

Positive Impact

In this study, not only negative effects that emerged in this study but also the researcher also found some positive impacts referring to the primary caregiver. One is that there was a tendency the caregivers become more religious. This impact seems to be closely related to the beliefs and background of the family culture. Another positive impact of this study is that families show a sense of unconditional love for children who have autism. This stage occurs when the families have finally been able to accept the condition of their autistic children. Similarly, in this acceptance stage parents work hard to raise children with special needs, and they begin to enjoy living with their children as what they are, and start forgetting difficult times they have previously when they first found out about their children of having autism. In addition, parents at the end give more affection and love to their special-needs children.^[25] Positive impacts were also found through some of the results of previous studies such as Hartmann which revealed that families gave more attention to autistic children compared to others.^[26] While according to Orsmond *et al.*, parents show affection for children and can appreciate children's abilities.^[27] The family also become more patient in caring for children, and trying to find help for handling their children is one of the positive effects of the acts of family acceptance toward having autistic children.^[28]

CONCLUSIONS

Women as main caregivers seem to be the party who feel the most impact of having autistic children such as emotional stress and physical problems, while the impact on men or husbands seems to be about a husband who must work extra to finance therapeutic needs, school, and household needs. However, even though having an autistic child seems to bring more negative impacts to families when compared to positive impacts, there are some few positive impacts felt by the families, especially once they are able to accept their autistic children's condition in their family.

Therefore, nurses as health-care providers certainly have a big role to reduce the negative impact felt by families with autistic children. Some efforts can be made such as providing counseling and conducting therapeutic communication with the families. Therefore, nurses can recognize problems faced by families and know how to help families solve problems through biological, psychological, social, and spiritual and cultural approaches.

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