

# Being a Mother of a Child with Autism Spectrum Disorder Level 3: A Phenomenological Study

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**Keywords:** Mother's Experience, Autism Spectrum Disorder Level 3.

**Abstract:** Autism Spectrum Disorder has been studied for many times before, but there is no study about being a mother of a child with Autism Spectrum Disorder Level 3, who has total dependence. The main purpose was to explore the experience being a mother of a child with ASD level 3. Purposive sampling technique was used to get ten participants in special region of Yogyakarta. Semi-structure interview was conducted. Credibility was established by doing multiple data collection methods, variation characteristic of participant, and confirmed evaluation and concluded using theories from previous studies and expert. The data was analyzed and interpreted using Giorgi's Phenomenology Method. Findings from this study identified four essences: perceiving reality differently, performing multiple roles, selfless, and strong faith. These essences of the participants' experiences were synthesized. A mother of a child with ASD level 3 generally experienced difficulties, high level of stress and hardship. The recommendation for the next study is to conduct studies on the significant others of children with ASD level 3.

## 1 INTRODUCTION

Milestone development is an important part in a child's lifetime. This is related to the ability (skill) in the structure and function of the body to be more complex, in a regular pattern and can be predicted as a result of the maturation process. It is the result of the interaction of various factors which are related, namely genetic factors, environmental, intellectual, and behavioral. Unique process and different result give a distinctive feature in each child (Hidayat, 2008).

Unfortunately, some children may experience abnormal developmental pattern. A common issue is the delay in development that could result into a disability. ASD prevalence rate in the last few years have increased significantly. In 2016, every one out of the 160 children is diagnosed with ASD (World Health Organization, 2016). In Indonesia in 2010 there were 44,519 males and 35,118 females below 19 years old who were recorded to exhibit developmental delays (Pusat Data dan Informasi Kementerian Kesehatan RI, 2014). One of the most common disabilities is Autism Spectrum Disorder or ASD.

ASD has been studied for many times before.

However the focus was more confined to parental satisfaction of ASD's diagnosis, family functioning and coping strategies of parents with children who have ASD, comparison of stress between the mother and father who were adjusting to their toddler's diagnosis of ASD, maternal stress of autism children, exploration and category of mothers' experiences with an autistic child, and parental experience with children with ASD, (Brogan & Knussen, 2003; Higgins et al., 2005; Davis & Carter, 2008; Bilgin & Kucuk, 2010; Chamal et al., 2010 as cited by Chua, 2012). However, there is no study about being a mother of a child with Autism Spectrum Disorder Level 3. Hence the researcher is interested to conduct the study in order to explore the experiences of being a mother of a child with autism spectrum disorder level 3. This study was conducted in Indonesia because this incidence is estimated to significantly increased from year to year as can be seen from the visiting number of patients in general hospitals and mental hospitals on clinical development of the child there (Subuh, 2016). Indonesia is still not well informed about the autism spectrum disorder. It was reported that parents, especially mothers, don't have enough understanding on how to handle their children with

autism spectrum disorder especially the children coming from families with low – medium economy level. In addition, families coming from rural area, had to bring their Autism children to the capital city to get treatment (CNN Indonesia, 2016).

## 2 METHODS

### 2.1 Research Locale

This study was conducted in the schools for children with autism in Special Region of Yogyakarta, Indonesia. That place is one of provinces in Indonesia, with 3.133,15 km<sup>2</sup> area, 3.543.708 total population, and approximately 550 km away from the Capital of Indonesia, Jakarta. All these schools are located in the three different districts and have been built in areas far from the center of the city. Those are under supervision of Education, Youth, and Sport Department of Special Region of Yogyakarta.

### 2.2 Population and Sampling

Purposive sampling technique was used to get ten participants. The participants was mothers of a child with ASD Level 3 diagnosed by doctors. Thus, the number of sample (ten participants) were considered to reach saturation because the given data is enough to describe the live experiences of being a mother of a child with ASD Level 3.

### 2.3 Research Instruments

The instrument in this study was the researcher itself, who did not have personal relationship or experience taking care of a child with ASD before. The demographic profile questionnaire, and a list of guide questions also used as research instrument. The following grand questions are: a) “What is it like to have a child with ASD Level 3?”, b). “What are these experience like?”, c) “How do you feel about being a mother of a child with ASD Level 3?” Semi-structure interview was conducted. The researcher allowed the participants narrate their experiences regarding of being a mother of a child with ASD Level 3 then, the subsequent questions were more focused and were guided by responses to broader questions. In the process of collecting data, the researcher used her cell phone as a recorder with participant’s consent and note. Before starting the process of data collection, the researcher has

obtained approval from the Far Eastern University Ethic Review Committee (ERC).

### 2.4 Data Collection

The data collection process was conducted from June to July 2017. On the process of collecting data, the researcher conducted face-to-face interview with the participants and recorded the interaction. The interview was done in the participants’ residence. It was done with only ones interview. In the interview process, the researcher used three guided questions. However, other types of questions were also used; such as follow-up questions, confirmation questions, or asking the participants to give examples of their statements. It has been done to follow-up, confirm, and clarify the previous answer. Thus, the researcher obtained a detailed and in-depth answer.

### 2.5 Research Design

This study used qualitative design. Descriptive phenomenology used in this study is based on Edmund Husserl’s philosophy.

### 2.6 Data Analysis

In this phenomenological study, the researcher applied the analysis method by Giorgi (1985) who developed the descriptive phenomenological method in psychology based on the thought of Husserl (as a cited in Broome, 2011).

## 3 RESULT AND DISCUSSION

Based on the demographic profile sheet, the youngest participant is 33 years old, the eldest is 50 years old, and the average age of the participants is 39 years old. While the ages of children with ASD level 3 is between 6-11 years old. Four participants have one child only, but the other six have more than one. Out of ten participants, only two participants came from Yogyakarta, while eight participants came from other provinces. Out of ten participants, only one mother is employed. On the level of education, it showed that six participants were high school graduate, three academic graduates, and only one graduated with a bachelor degree. The researcher did not use the real name of the participants, instead pseudonym were used to protect their identity.

Findings from this study identified four essences: perceiving reality differently, performing multiple roles, selfless, and strong faith.

### 3.1 Perceiving Reality Differently

Based on the participant's descriptions, there are two different perceptions of participants when they first found out that their child was diagnosed with ASD level 3, normal feeling and emotional distress, like shocked or fell hard. Tania said, *"Firstly, I felt normal like nothing happened because I did not know much about autism."* The same perception also stated by Nina, *"...I felt the same. Not afraid, not worry, not sad. Because at the time I didn't know anything about autism. Although the doctor briefly explained to me about autism and what I should do, I still believe that it just a type of disease that will be cured."*

Meanwhile, most of the participants have different perception. For example Chelsea. She said, *"It's hard. It is like doing my examination. Yeah because I have to learn something new, and then I have to solve the problems regarding."* Or Farra, who stated *"When I have been told that my son has autism, especially in high level, I was shocked."*

Perception is how people understand and give meaning to something, and is affected by factors which cause everyone to have different response (Sharma, 2016).

There are factors that influence perception; such as the perceiver's attitudes, motives, interests, experience, and expectation that cause different perception among individuals exposed to the same reality (Rao, 2008). In this study, it was found that participants had different initial perceptions. They have no prior experience of having children diagnosed with level 3 ASD. They have the same motivations and interests about their children. However, they differed in attitudes and expectation when they found out that their children were diagnosed with ASD level 3. Three mothers thought it could be completely cured, but other mothers thought that having ASD level 3 children meant that they had to do many new things which was never thought of before.

### 3.2 Performing Multiple Roles

In the present study, since they became mothers of children with ASD level 3, they have right and responsibilities to properly raise their children. Limitations possess by children with ASD level 3 make them play multiple roles; a care giver, an

educator, an observer and a problem solver. Mothers help their children meet their basic needs. Mother taught them how to do it by themselves. Mother also taught them to socialize, sought for special school or therapy for them, and many others. They also experience stress in performing their multiple roles.

It is mostly conveyed by participants in this study, such as Ann. She said, *"My son cannot do anything yet. He can't take a bath, change clothes without my assistance."* Then, add by Tania, *"So, everything was my duty in preparing all his needs. He didn't want to eat if was not me who fed him."*

But through this study, note that a mother of a child with ASD level 3 has multiple roles. For example, Farra. She said *"Finally, when he was 1,5 years old was not able to speak. I started to worry. He also didn't come when I call his name. He did not turn his head. I thought, is he deaf?".* But he is not, because when I observed him, he loved to watch the advertisements on TV. When he was playing and hear his favorite advertisements on TV, he leaved his toys and came closer to the TV." That statement shows that Farra perform her role as an observer.

They are also required to act as a problem solver. Like Desy, who said *"I took him to be checked in Growth clinic."*, and Tania, *"I took him to attend Play Group in 3 and half years old."* Any other roles were are found based on the statements of the participants.

Roles refered to a set of rights and responsibilities that are socially accepted and related to a particular position in a group and are dynamic of a status. (Hargašová, 1991, p. 97 as a cited in Gežova, 2015). People perform various roles in their lives, including women. In the family, woman as a mother plays a unique, treasured, and important roles, because she is the keystone of the family especially for her child/ children (Štrbová, 2004, p. 18 as a cited in Gežova, 2015). If the mother of a child with a normal growth and development pattern will experience a change in the mother role at a clear time as their child ages, but not in the mother of a child with autism.

This result is in line with Diranian (2011) who mentioned that mother is a protector and a disciplinarian, she is selfless and is willing to make sacrifices, just to make sure that their children are equipped with the knowledge, skills and abilities to become a competent human being. More specifically as explained by Bihn (2012) that the first role of the mother's is to bring love to the child, and the second role is to be the child's first teacher. In her study about The Role of Family in Educating-Socializing Children, she explained that mothers perform their

roles with holding, lulling, looking after, and worrying about children. Mothers are interested in every child's behavior; when they are full, hungry, hot, cold, comfortable, uncomfortable, or when they are laughing. Mothers teach children good manner towards family members, neighbors, and everyone.

### 3.3 Selfless

In this study, based on the participants' expression, it is known that a mother of child with ASD level 3 makes many sacrifices for their child. Like Rafika, she expressed, *"Sometimes I need to have me-time, cream bath, massage, etc. But, yeah what I can do if the schedule is really tight, school, therapy, house hold cares. So, I do that."* What she wanted to tell us is that she puts her self-centered behind, instead prioritise her son needs.

Marie showed another example of an action that has the same meaning and reason like Rafika. She told us *"I usually apologize to my neighbor because of my daughter's behavior. She screams loudly at midnight"*. And also added by Desy with her statement, *"Then, finally we moved here, in Yogyakarta. I chose the house, it's rather expensive but I hope that the neighbors are busy that they do not get disturbed by my son when he is screaming."*

Marie and Desy put aside their embarrassment and financial matter to overcome their neighbours's inconvenience due to her child's behavior. Beside, we also found that most of the participants were willing to move from their city to Yogyakarta to get the proper therapy or special school for their children. These actions are manifestations of the selflessness that has been done by mothers of child ith ASD level 3.

Selflessness is referred to an attitude where the self is not on a central point (Neff, 2003 as a cited in Dambrun & Ricard, 2011). In this study, based on the participants' expression, it is known that a mother of child with ASD level 3 makes many sacrifices for their child. Mothers put aside their embarrassment and financial matter to overcome their neighbours's inconvenience due to her child's behavior. Beside, we also found that most of the participants were willing to move from their city to Yogyakarta to get the proper therapy or special school for their children. These actions are manifestations of the selflessness that have been done by mothers of children with ASD level 3.

Selfless is characterized by low levels of self-centeredness, a low degree of importance given to the self and is closely related to characteristics such as altruism, kindness, respect, empathy, compassion

(Danbrum, 2011). A selfless functioning is based on a weak distinction between self and others, and self and the environment as a whole (Leary, Tipsord, & Tate, 2008).

Previous study about mothering and self sacrifices in Aristotle's Nicomachean Ethics defined that mothers love their children more than fathers, mother-child relationships are a more giving rather than receiving affection (Ward, 2008).

### 3.4 Strong Faith

The mother of child with ASD level 3 believed that God will help them to taking care their special child. They believed there will be good things. Chelsea said, *"But, besides that, I believe God will always help me. And in the end -I don't know when-, He will proud of me and give me the best gift ever."* Then added by Rafika, *"I believe that is a test from God. When I passed, He will give me eternal present."*

Faith is defined as a complete trust or confidence in someone or something, but also refers to the strong belief in God or in the doctrines of a religion, based on spiritual apprehension rather than proof (Merriam-webster, 2017). Although the participants have different religion, they have strong belief in God regarding their experience of being a mother of a child with ASD level 3.

Faith makes them strong, keeps them going as mothers of child with ASD level 3, as implicit on Desy's expression *"We believe that after this sadness there will be happiness. There will be a happy ending for us. We depend on Allah."*

The mother of child with ASD level 3 believed that God will help them take care of their special child. They believed there will be good things. Faith is a complete trust or confidence in someone or something, but also refers to the strong belief in God or in the doctrines of a religion, based on spiritual apprehension rather than proof (Merriam-Webster, 2017). Although participants have different religions, they have strong belief in God regarding their experience of being a mother of a child with ASD level 3.

A literature says that parents of children with autism face stressors associated with several aspects of child's symptoms, including sleep difficulties, behavioral problems, poor social skills, and financial challenges; each stressor may be related to psychological deterioration of the parents (Serrata, 2012 as a cited in Davis, 2016).

That was the background of the attitude of the mother who then resigned to God and sought God's help. Mothers continue their journey toward the

level of spirituality, that means they have considered the parenting process as the responsibility given to them in their lives and no one can replace them from given. Although most of them know that their children's abnormalities can not be cured, they do not stop their efforts and consider to move forward to help their children, they believe they have to do something to help children reach the top of their goals in every possible way (Haeydari, Shahidi, and Mohammadpour, 2015).

#### 4 CONCLUSIONS

Based on the participants' responses, data revealed that a mother of a child with ASD level 3 generally experienced difficulties, high level of stress, and hardships. Even so, they are able to adjust and find a suitable way to cope with taking care of the child with ASD level 3. As a nurse we are expected to facilitate mothers' inquiry or mothers' concerns about the future of children with ASD. The knowledge of the growth and development stages of children should be explained to them.

#### REFERENCES

- Broome, R., E. 2011. Descriptive phenomenological method: an example of a methodology section from doctoral dissertation.
- Chua Ah, K. 2012. Parental experience of having a child diagnosed with Autistic Spectrum Disorder: An integrative literature review. *Singapore Nursing Journal*, 39(1), 8-18.
- CNN Indonesia (2016). *Indonesia Masih 'Gelap' Tentang Autisme*.
- Davis, R. F. (2016). Religious coping by mothers of children with autism. Proquest number: 10116384.
- Diranian, S. 2011, September 06. *The meaning of being a mother*. Retrieved from <http://www.livestrong.com/article/536701-the-meaning-of-being-a-mother/>
- Gežova, K. C. (2015). Father's and Mother's Roles and Their Particularities in Raising Children. *Acta Technologica Dubnicae*. Doi: 10.1515/1td-2015-0032
- Gupta, A., Kalaivani, M., Gupta, S. K., Rai, S. K., & Nongkynrih, B. 2016. The study on achievement of motor milestones and associated factors among children in rural North India. *Journal Of Family Medicine & Primary Care*, 5(2), 378-382. doi:10.4103/2249-4863.192346.
- Hidayat, A. A. A. 2008. *Pengantar ilmu kesehatan anak untuk pendidikan kebidanan*. Jakarta: Salemba Medika.
- Pusat Data dan Informasi Kementerian Kesehatan RI. 2014. *Penyandang disabilitas pada anak*. Jakarta: Author.
- Rao, R. (2008). *Factors influencing perception*. Retrieved from <https://www.citeman.com/2849-factors-influencing-perception.html>
- Sharma, A. (2016). *Perception: Meaning, definition, principle and factors affecting in perception*. Retrieved from <http://www.psychologydiscussion.net/perception/perception-meaning-definition-principles-and-factors-affecting-in-perception/634>
- Subuh. (2016, April 13). *Kenali dan deteksi dini individu dengan spektrum autisme melalui pendekatan keluarga untuk tingkatan kualitas hidupnya*.
- Ward, A. (2008). *Mothering and the sacrifice of self: women and friendship in Aristotle's nicomachean ethics*.
- Haeydari, A., Shahidi, L. H., Mohammadpour, A. (2015). Spiritual journey in mothers' lived experiences of caring for children with autism spectrum disorders. *Global journal of health science: Vol.7, No. 6;2015*. ISSN 1916-9736 E-ISSN 1916-9744
- World Health Organization. (2016). *Autism spectrum disorders*.