



The Experiences of Mother who Has Children with Autism Spectrum Disorder

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Abstract

Purpose. The purpose of this study is to describe the experience of mothers who have autism spectrum disorder children. **Methods.** This qualitative research applied the phenomenological method. The subjects in this study were three early adult mothers with children with autism. A semi-structured interview was used as the data collection method. This study used Interpretative Phenomenological Analysis (IPA) for the data analysis technique. **Findings.** The results showed that there were 3 main themes: 1) emotional fluctuations (sad, angry, disappointed, worried), 2) parenting for autistic children (mothers experienced stress (easily getting tired, problem-solving disorders, helplessness, behavioral disorders)), and 3) planning for the children's future (professional care, special schools, autism communities).

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INTRODUCTION

Children are the greatest gift from God that is entrusted to every family. Many prayers, hopes, and big plans are always poured out by parents since their children were born to become great individuals in the future. These expectations can change when a child is diagnosed with a developmental disorder that will affect all aspects of his life; even though, regarding the conditions, the parents should be able to accept their child who has a deficiency.

According to Santoso (in Rachmawati & Masykur, 2017) children with special needs are those with disabilities or, in other words, children with physical and mental disabilities who have special needs are needed to be grouped with other children with special needs in the learning process. There are many kinds of children with special needs; one of them is autism. Autism is a neurobiological developmental disorder that has a severe levels. This disorder can affect several aspects of child development, such as how children learn and communicate, the presence of children in the environment, social relationships with other people, and children's ability to take care of themselves (Dewi et al., 2018).

Hadith (in Wardani, 2009) states that many factors cause autism, such as genetics or heredity, viruses, poor nutrition, bleeding, food poisoning during pregnancy, lack of oxygen, air pollution, water, and food. In addition, the cause of autism can also come from pregnancy or birth factors. The opinion of Women's Empowerment and Child Protection PPPA (in Nurjadin, 2021) states that based on the calculation, there are two new cases of autism per 1,000 population per year and 10 autism cases per 1,000 population. The total population of Indonesia was 237.5 million in 2018 with a growth rate of 1.14%. The 2010 Central Statistics Agency estimates that there are 2.4 million people with autism, with an increase of 500 people every year.

Autism can happen to anyone, whether urban or rural, poor or rich. The diagnosis of autism in children is not necessarily released when the child is still a baby, but it can also start to occur when the child has entered early childhood. This is something that most parents are afraid of. According to Upoma et al. (2020), many parents show emotional reactions such as shock, sadness, anger, guilt, stress, depression, and feelings of empathy. Some parents have prepared to listen to the worst possibility of their child's diagnosis condition since they have known some of the symptoms since their child was a baby.

In this stage, mothers often feel devastated by what has happened to their children. Sinaga & Pandede (2021) state that mothers experience disappointment and feelings of failure in educating and raising children. Besides that, they are also often blamed and considered to be responsible for what happens to their children. The love that mothers always give to their children makes them willing to be the main caregivers as a part of their responsibilities, and they are also willing to put their children's needs before their own needs (Anderson et al., 2020).

Mothers' availability as caregivers for autistic children gives mothers many experiences and problems within themselves. Oduyemi et al. (2021) state that mothers have more negative experiences and difficulties in raising autistic children compared to fathers who play a role in caring for autistic children because some children are afraid of their fathers. These problems include psychological well-being, emotions, stress, unpleasant actions, finances, children's future, parenting, and so on, which mothers often experience with autism.

The problems that occur in mothers depend on each individual's upbringing and even the prevailing culture. Giannotti et al. (2021) argue that Italian parents of autistic children are more likely to engage in responsive and affectionate behavior towards their children. In contrast, Japanese parents are more likely to benefit from interventions to reduce self-blame and concern towards their children. Melis (in Roquette Viana et al., 2021) adds that the concept of culture makes parents interact, act, and give meaning to the experience of the parenting process, which can reflect smooth integration and mastery of competencies in parenting. Based on the description of the results of previous studies, which were inconsistent, the researchers wanted to conduct further research to find out the experiences of mothers who have children with autism.

The purpose of this study is to describe the experiences of mothers who have children with autism. In addition, to find out some of the problems experienced by mothers or parents with children with autism to foster understanding and provide positive support to improve their quality of life.

METHODS

This research was conducted using a qualitative method with a phenomenological approach. According to Mardawani (2020), phenomenological research focuses on phenomena and

realities that are happening to be studied to explain their meaning. This study applied the Interpretative Phenomenological Analysis (IPA) method to analyze the data. Smith et al. (2009) define Interpretative Phenomenological Analysis (IPA) as a qualitative approach used to understand how a person understands his life experiences. According to Kahija (2017), there are several stages in conducting data analysis using the Interpretative Phenomenological Analysis (IPA) method: 1) Reading the transcript many times, 2) Making some initial notes (initial nothing), 3) Creating emergent themes, 4) Create superordinate themes, 5) Inter-case/inter-experience patterns from research participants, 6) Superordinate themes, and 7) Report the results of the analysis.

Data collection techniques were conducted through semi-structured interviews. The subjects involved in this study were 3 mothers who had children with autistic disorders through the purposive method. All data is kept confidential by using a code.

RESULTS AND DISCUSSION

From the data analysis obtained from the three subjects, there are three main themes related to the experience of mothers caring for autistic children, including 1) Emotional fluctuations, 2) Parenting for children with autism, 3) Planning for the children's future. Subject 1 (ES) is a mother who is 25 years old. Subject 2 (SN) is a 31-year-old mother. Subject 3 (DRS) is a 42 year old mother.

Emotional Fluctuations

This study found that the three mothers felt their emotions were up and down or unstable when thinking about their child's condition, which was different from normal children in general. Archi et al. (2021) state that most parents cannot accept the situation when their children are diagnosed with special needs that will affect their condition. Especially for parents who have autistic children, Watson et al. (in Chodidjah & Kumalasari, 2018) find that being a parent of a child with autistic disorder tends to have negative experiences.

The subject felt many feelings, such as sadness when thinking about the circumstances and destiny that he has a child with autism. Rahmayanti et al. (in Archi et al., 2021) state that they feel sad when they know that what they are experiencing now is beyond their life expectancy, especially concerning someone precious in their parents' lives. The most profound feeling of sadness

was when she received a diagnosis that showed her child had autism. At this time, mothers only contemplate the reality that must be accepted and do not know what they should do for the child's good in the future. Many thoughts come to mind, one of which is the response that will be obtained when the husband and other family members find out the diagnosis results, which indicate that their child has special needs (Abdullah et al., 2022).

In addition to feeling sad, mothers generally get angry about negative views always aimed at their children with autism. People cannot control other people when they think about their life; sometimes, they feel normal with other people's perspectives and don't feel hurt. When someone underestimates them, mainly because of the conditions suffered by autistic children, it can hurt their feelings, leading to anger. This follows the research of Aurelia et al. (2022) report that mothers tend to get angry when others are cynical and talk about negative things about their children who have autism. Chan & Lam (in Shattnawi et al., 2021) add that the stigma faced by mothers and children with autism will affect behavior that will negatively impact and feel ostracized by the surrounding environment.

In addition, mothers often get angry when their children have tantrums because they do not obey their mother's words and tend to fight over trivial matters. Moreover, this problem occurs in working mothers because of the lack of time to give their children attention and affection. They feel increasingly distant from their mother's support; in contrast with mothers who do not work and focus on raising children, they have more free time and affection to be given (Firdaus & Santy, 2020). However, this does not mean that working mothers cannot properly educate their children. According to Abdullah et al. (2022), all these actions can make a mother metamorphose into a mother who is patient and brave in dealing with situations when her child is in a tantrum.

Feelings of disappointment are also often experienced by mothers, usually at the beginning when they find out that their child has been diagnosed with autism because of the circumstances that must be accepted. At first, the mother will feel that her life is unfair and not in line with expectations and even tends to blame God for everything destined. This condition will gradually disappear and be forgotten after she can understand and accept her destiny when she meets people with the same condition as her in the right environment for raising and educating children (Aurelia et al., 2022).

The feeling of worry experienced by the

mother is related to the daily life of their children, especially when thinking about their future. According to Halstead et al. (2018), the severity of Autistic Spectrum Disorder symptoms in children gave mothers a sense of worry and loneliness. This autistic condition requires special attention and care that can protect the child and others around him. Excessive parenting can significantly affect negative thoughts, depression, and anxiety/worries that ultimately make mothers of children with ASD disorders have greater accessibility to think about death, which leads to low psychological well-being (Cox et al., 2015). In addition, mother's concerns can arise when children socialize in their environment because there are many cases where some parents are reluctant to permit their children to play with children who have autism.

All the sadness, anger, disappointment, and worry emotions that occur to the mother are negative emotions caused by the mother's thoughts towards their children's condition. Accepting the situation takes time, and a process, Muniroh (in Dewi et al., 2018) states that when the process of adaptation and acceptance of the child's condition has been passed, parents begin to look at it positively and accept the existence of the child which indirectly fosters motivation for their child's recovery.

Parenting for Autistic Children

When caring for autistic children, the mother's condition is not easy; there are many challenges that mothers have to face both physically and mentally. The process that is carried out does not always lead to a positive side for the mother. Mothers often feel tired easily caused by stress that attacks them. Starting from the burden of thought and the more problems they might face, the more it can affect the mother's physical condition. Alamdarloo et al. (Keville et al., 2021) state that the complexity of ASD children is the reason for mothers having high stress compared to mothers who care for other children with special needs. This requires a considerable mother's physical and psychological involvement to optimize these efforts so that they run according to expectations.

Shattnawi et al. (2021) argue that the burden of child care further increases the involvement and responsibility of mothers in meeting daily needs, making mothers feel a lack of time for themselves. When a mother has an autistic child, she already has a special parenting pattern that requires her to always be patient in dealing with it. Mothers have made various efforts to care

for and educate their autistic children. According to research by Wardani (2009), these efforts have not yielded results, including not being able to be disciplined and concentrate while studying; sometimes, children are disobedient and like to refuse orders. There is also no independence or eye contact when interacting, which often violates a predetermined diet. On the other hand, mothers also realize that their children experience fatigue. Keville et al. (2021) state that the typical behavior of autistic children makes them tired in terms of physical, cognitive, and social interactions, making mothers understand more about their children's condition.

In nurturing children with autism, mothers can experience problem-solving disorders. Less effective decision-making can occur due to a lack of interaction and communication with others. Effective communication and interaction are the primary keys to success in raising children with developmental disorders (Parasian & Ramadhana, 2021). Many negative stigmas affect maternal stress levels, so many mothers withdraw from the social environment to make changes. Mothers only can interact with family, and most of their time is dedicated to their children. Most likely, there will be some new problems that are difficult for the mother to solve independently, so doing a lot of interaction, especially for mothers with children with autism, is needed. There will be an exchange of experiences regarding developments or problems and the possibilities that the children will experience.

Mothers often feel helpless when it comes to the conditions experienced by their children. Sometimes they feel that they do not know what to do for the good of their children, and the feeling of wanting to give up always arises in their minds. Jackson et al. (2020) identify that when mothers shared their concerns or consulted professionals, they felt they were not heard, resulting in a breakdown in their relationship and loss of trust in professionals. This problem creates a feeling of helplessness in mothers. Some even feel hopeless and want to hurt themselves by banging their heads against the wall due to frustration with the situation. In addition to the many negative stigmas aimed at her, Erina et al. (2019) state that many negative stigmas attack mothers with autistic children, thus making the mother's condition even more stressful to depression.

Behavioral disorders experienced by mothers are caused by exhausted patience when caring for and dealing with the behavior of autistic children. Adams et al. (in Keville et al., 2021) argue that mothers with children with autism often

get aggression and tantrums from children, especially when they are tired; their behavior will be more challenging. It is not uncommon for mothers to yell and hit their children if their behavior is against their mother's expectations. This behavior can appear when the mother is depressed because she wants to control behavior that might unconsciously harm the child to be in line with the mother's expectations. This situation can occur because autistic children often engage in dangerous, aggressive behavior, self-injury, and damage to things around them (Chodidjah & Kusumasari, 2018).

Children's Future Planning

The autistic condition experienced by children does not mean the end of everything. Many efforts can be made by parents in designing the future of their children so they can create the expectations that have been built and planned. We cannot equalize the abilities of autistic children with normal children, as well as realizing their dreams can be done depending on the child's skills, and it requires a lot of patience.

Professional treatment can be used as a solution to support a child's better condition and development. The involvement of professional handlers aims is needed to make the children handled appropriately in the right way. Managing social interactions can be in the form of Applied Behavior Analysis (ABA) Therapy. Iskandar & Iindaryani (in Heri et al., 2021) state that this therapy is an applied science used to study autism behavior so that behaviors identified as having problems or irregularities can be known to be given proper treatment. Sutadi (in Julimet & Cholid, 2017) adds that therapy using the Applied Behavior Analysis (ABA) method has the advantage including systematic, structured, measurable, and can be modified as needed.

In addition, you can also do a diet of foods that are low in gluten and casein. Food is a source of energy for the human body. Providing nutrition to children with autism is essential because some foods should not be consumed. According to Sinaga & Pandede (2021), many mothers still do not understand a good diet for autistic children. They assume that autistic children do not have special differences in terms of food from other normal children. Mothers do not provide food intake whose nutrition is under the rules for the needs of children with autism. Some foods that autistic children should not consume, according to Nurhidayah et al. (2021) of which, are foods that contain gluten and casein. This can lead to increased intestinal permeability (leaky gut), ma-

king it difficult for the body to digest. The right solution to avoid foods that contain gluten and casein is to apply the Gluten Free Casein Free (GFCF) diet.

Sudarmintawan et al. (2018) state that a gluten and casein-free diet is an option for biomedical therapy by eliminating and avoiding foods containing gluten and casein. Gluten is a protein found in several types of wheat, while casein is a phosphorus protein found in milk and its products. The solution is supported by Noor et al. (2014) state that mothers do not always depend on their child's recovery only through drugs without food control and the provision of intensive, continuous, and consistent education to produce optimal treatment. Ginting et al. (in Sudarmintawan et al., 2018) added that parents who want to apply a gluten and casein diet to a child with autism must be examined first by a doctor or practitioner to determine whether the child's condition can undergo the diet.

Children with autism also have full opportunities to study and gain knowledge, but it will be better if they are sent to special schools. Not without reason, it is because the children's social and interaction problems in their homes will also happen when they go outside. Abdullah et al. (2022) state that mothers who registered their children in kindergarten often received a rejection from the school institution due to their child's condition. It can be understood that autistic children need a school whose environment can accept their situation. Parents can choose inclusive education that provides more opportunities for children to communicate and socialize with their peers (Chodidjah & Kusumasari, 2018).

A lot of information is easy to find on the internet, including expanding connections to get new knowledge from others' experiences, one of which is joining the autism community. The social interaction problems in mothers with autistic children can create tension and social isolation. As a result, the mother might feel that she does not get support, even though she needs a lot of help to share information and knowledge in that position. Roquette Viana et al. (2021) state that the primary reference source comes from the circle of friends. Some mothers say they did not get support from friends because they were intimidated by the circumstances of having a child with autism. Therefore, mothers can start to expand their connections and become members of the autism community on Facebook, Instagram, and other types of social media to get new knowledge and social support.

This solution can overcome some of the

mothers' problems regarding the lack of information about autistic children. Anderson et al. (2020) state that mothers experience a lack of information about autism. They only get an overview after receiving a diagnosis from professionals without further explanation. Then the mothers have to take the initiative to find out by themselves and join online groups to get information on useful strategies for educating their children.

CONCLUSION

The presence of an autistic child in a family is beyond expectations for every parent, especially for mothers. Many challenges are faced by mothers when taking care of children with autism. The experience of mothers who have children with autism in the sample of this study showed that all three experienced the same experiences, namely emotional fluctuations (in the form of sadness, anger, disappointment, and worry), parenting of children with autism (where mothers experienced parenting stress, problem-solving disorders, helplessness, and behavioral disorders), and mothers begin to plan for their children's future (by going to professional care, special schools, and the autism community). The advice given by the author for mothers is to learn a lot about autism so they can provide proper treatment and have a positive experience. For further researchers, parenting for children with autism is very important to be conducted; thus, further researchers are expected to explore more deeply the experience of mothers of autistic children in terms of many sides such as the parenting applied or the socio-economic side.

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