

Mothers' Experiences of Having Children with Autism in A Special School (SLB) Negeri Jepara

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Abstract. Background: Autism or ASD (Autism Spectrum Disorder) is a range of conditions characterized by some degree of impaired social behavior, communication and language, and a narrow range of interests and activities that are unique to the individual and performed repetitively. The majority of the phenomenon of maternal stress is higher than paternal stress. The purpose of this study was to explore more deeply the experiences of mothers who have children with autism in SLB Negeri Jepara. **Methods:** This study used a qualitative method with a phenomenological approach. The informants of this study are mothers who have children with autism. The selection of informants was carried out using purposive sampling technique (nonprobability sampling). The data collection technique used is in-depth interviews and data collection tools used such as interview guideline formats, notebooks, pens and other supporting tools such as cellphones as recording devices during interviews. **Results:** The results of this study are in accordance with the themes that the researcher has identified. According to the participants, it was not easy to immediately accept the child's condition when diagnosed with autism, so they experienced a variety of feelings, participants also made efforts to seek treatment for the child, during the process of caring for the child, participants said that the child had special care and some received social support. **Conclusion:** In this study it can be seen that there are four corresponding themes in the results. However, the four themes are less varied, so further research needs to be done on the experiences of mothers who have children with autism by developing these themes.

Keywords: Mothers' experiences, children with special needs, autism.

BACKGROUND

According to the World Health Organization (WHO), autism or ASD (Autism Spectrum Disorder) refers to a range of conditions characterized by some degree of impaired social behavior, communication and language, and a narrow range of interests and activities that are unique to the individual and performed repetitively (World Health Organization, 2017). Autistic disorder is characterized by abnormalities in social functioning, communication and language, and restricted behaviors and interests in children (Mash & Wolfe, cited in Sa'diyah, 2016). Individuals with autism often exhibit other co-occurring conditions, including epilepsy, depression, anxiety and attention deficit hyperactivity disorder (ADHD) (WHO, 2017). According to Viora (2012), the causative factors of autism are not yet known with certainty, but there is a possibility that the interaction between biological and genetic factors, as well as external factors such as heavy metal pollution and air pollution, can be a factor in triggering autistic disorders in children (www.depkes.go.id). According to Diah (2013), there are quite a variety of interventions that can be done for problems faced by children with autism such as speech therapy for communication problems, behavioral therapy for affective problems, and occupational therapy to overcome motor development problems (<https://www.jpnn.com>).

In Jepara district there is an Ordinary School, namely in SLB Negeri Jepara, based on

a survey of researchers to the SLB, data on the number of students in the 2015/2016 school year were 289 students, while the number of autistic students was only 7 students, the number of students in the 2016/2017 school year was 315 students, while the number of autistic students was only 9 students, and the number of students in the 2017/2018 school year was 347 students, while the number of autistic students was only 11 students. So from these data it can be concluded that the prevalence of the number of children with autism / autistic students in SLB Negeri Jepara increases every year.

Research conducted by Kusumastuti (2014) on single mothers who have children with autism, states that factors that cause stress in mothers who care for autistic children such as child conditions, overall living conditions that cause stress, social support, family functions, material resources such as living facilities, including clothing, food, and shelter. From the many factors that become stressors for mothers in caring for autistic children, researchers are interested in conducting further research on the phenomenon of the experiences of mothers who have children with autism, because the experiences of mothers who have children with autism will be different for each individual, and researchers are also interested in conducting qualitative research because in order to be able to explore more deeply the phenomenon of the experiences of mothers who have children with autism in SLB Negeri Jepara.

RESEARCH METHODS

This study uses a qualitative method with a phenomenological approach, because researchers want to understand the subjective experience, namely the experience of mothers who have children with autism from the point of view of the subject (mother) itself which is happening naturally (*natural*) without any manipulation. Informants in this study are mothers who have children with autism, using *purposive sampling* technique (*nonprobability sampling*). The number of informants to be selected by researchers in this study is not limited, but the research will be stopped by researchers when data saturation will be achieved (Braun & Clarke, 2006). The selected informants must meet the inclusion criteria, among others: mothers who have children with autism in SLB Negeri Jepara, mothers who have a minimum high school education, mothers who are willing to become research informants and mothers who are physically and mentally healthy.

This research was conducted at SLB Negeri Jepara, for two weeks, namely on April 23, 2018 - May 05, 2018. The data collection technique used is an *in-depth interview* which is a type of guided free interview and data collection tools used such as interview guideline formats, notebooks, pens and other supporting tools such as *cellphones* as recording devices during interviews. To manage the interview data, researchers used thematic analysis conducted by Braun and Clarke (2006) which consists of 6 stages, namely: recognizing data, initializing codes, searching for themes, reviewing themes, defining themes and theme names, and producing reports.

RESULTS AND DISCUSSION

SLB Negeri Jepara is a special education institution that is given the task and authority to handle and organize the education of children with special needs (ABK) starting from the TKLB, SDLB, SMPLB and SMALB levels for types of disabilities such as visual impairment, hearing impairment, mental disability, physical disability and autism.

There are five mothers who have participated in the study, including: participant one

with code P1, initials T, aged 40 years, address kec. Jepara kab. Jepara, last education bachelor, daily as a housewife, married status and has a son with autism aged 12 years; participant two with code P2, initials M, aged 55 years, address kec. Jepara kab. Jepara, last education high school, daily as a housewife, married status and has a son with autism aged 15 years; participant three with code P3, initials F, aged 52 years, address kec. Jeparakab. Jepara, with the last education of senior high school, is a housewife, married and has a son with autism who is eight years old; participant four with code P4, initials W, 34 years old, address Bangsri district. Jepara, has a bachelor's degree, works as a teacher by day, is married and has a nine-year-old male autistic child; participant five with code P5, initials S, 45 years old, address Pecangaan kec. Jepara, has a bachelor's degree, works as a housewife by day, is married and has a nine-year-old male autistic child.

Based on the results of interviews conducted by researchers about the phenomenon of the experience of mothers who have children with autism in SLB Negeri Jepara, participants stated that it was not easy to immediately accept the child's condition when diagnosed with autism, so they experienced a variety of feelings, participants also made efforts to seek treatment for children, during the process of caring for children participants said that children had special care and some also received social support from researchers. So from this statement, the researcher identified the description of the results of the interview in five main themes, namely the variety of maternal feelings, efforts to seek treatment, special care, and social support.

1. Variety of mother's feelings

Based on the results of interviews that have been conducted, almost all mothers' feelings when they find out that their children are diagnosed with autism are shocked. This is in accordance with the statements of the first and second participants, as follows:

"...//...yes first, I was surprised to have a child like that...//.." (P1)

"...//...shock...//..." (P2)

The third and fourth participants also expressed shock when they found out that their child had autism, as follows:

"...//...didn't expect it at all...//.." (P3)

"...//...it's frankly shocking...//.." (P4)

Most of the participants, namely three out of five participants, stated that they felt sad when they found out that their children were diagnosed with autism. The following statements were delivered by the third, fourth and fifth participants: "...//...I feel sad...//.." (P3)

"Sad" (P4)

"...//...I feel sad...//.." (P5)

In addition to shock and sadness, some participants, namely two participants, stated that they also felt stressed when they found out that their child was diagnosed with autism. This is in accordance with the statements of the second and fifth participants, as follows:

"...//...yes it is confused...//...like stress...//.." (P2)

"...//...feel dizzy...//..." (P5)

Both statements about feelings of shock and sadness are in accordance with research conducted by Noor *et al.*, (2014) entitled the experience of mothers in caring for school-age autistic children about the acceptance process, which includes feelings of shock, sadness, fear, anxiety, guilt or blame for the child's condition. This is also in accordance with Istiqomah's research (2014) entitled Emotional regulation of mothers who have autistic children, which states that the description of emotions such as

pleasure, hope, anger, sadness, shame, fear or anxiety found in mothers generally who have autistic children.

According to Deater (cited in Fitriani and Ambarini, 2013), stress in parents is caused by the burden of challenges faced by parents in the process of caring for children. In Kusumastuti's research (2014) entitled single mother stress who has an autistic child, concluded that the description of stress in subjects who have autistic children is due to the subject's inability to respond to problems that arise in his life related to caring for autistic children.

2. Efforts to seek treatment

Based on the results of the interviews conducted, almost all participants stated that efforts to seek treatment for autistic children such as being taken to a doctor. This is in accordance with the second and third statements, which are as follows:

"...at doctor H...I took it to doctor I...I went straight to the hospital, this hospital has a neurologist, psychologist, nutritionist and speech therapist..." (P2)

"...and then examined by the ENT (doctor) first..." (P3)

The fourth and fifth participants also stated that they went to the doctor to seek treatment for their children:

"...I also did a test, hearing test (ENT doctor) in Kartini...in 2013 I went to Kariadi to Semarang, my son was tested for BERA (Brain Evoked Response Audiometry)..." (P4)

"...Yes I went to the doctor..." (P5)

There were also some participants, namely three participants, whose efforts to seek treatment for autistic children were taken to psychiatrists. This is in accordance with the statements of the first, second and third participants, as follows: "...I took him to a psychiatrist...when his father was moved there (Buton Island) I met a psychologist...yes I was treated there (psychologist)..." (P1)

"...this hospital has a neurologist, psychologist, nutritionist and speech therapist..." (P2)

"... (doctor) ENT and then after that to psychiatrist-psychology..." (P3)

Both statements about efforts to seek treatment for autistic children are in accordance with Rachmayanti and Zulkaida's research (2011) entitled the role of parents in autistic children's therapy, which reveals several roles of parents in autistic children's therapy, one of which is ensuring diagnostics, where parents must be able to choose competent doctors such as pediatricians who treat autism, pediatric neurologists, and medical rehabilitation doctors. This statement is also in accordance with Boham's research (2013) entitled communication patterns of parents with autistic children, stating that good, systematic and planned handling (autistic children) will support the achievement of optimal growth of autistic children, because according to him good handling requires openness, cooperation and shared responsibility from parents, pediatric psychiatrists, pediatricians, therapists, psychologists, teachers at school and siblings in the extended family.

3. Special care

Based on the results of the interviews that have been conducted, almost all participants stated that autistic children need special care for 24 hours, namely the child must always be supervised by parents in a way that the participant (mother) divides time with her husband (father). This is in accordance with the following statements from the second and third participants:

"...the point is that autistic children cannot, cannot be separated from their parents

for 24 hours, there must be someone who supervises.../...dividing time (supervising) me and my husband.../..." (P2)

".../...(supervised) with my brother sometimes with his father.../..." (P3)

This is also in accordance with the statements made by the fourth and fifth participants, as follows:

".../...dividing the time (supervising) yes when I come home later because the father has divided the tasks..." (P4)

".../...if the father is at home then I am out, if the father is out then I am at home, so it's alternating (supervising) both.../..." (P5)

Autistic children also need special care related to meeting their nutritional needs (food), and all participants stated that there are certain food restrictions that

are not given to autistic children, so the child must go on a diet, such as a diet of wheat protein (gluten), cow's milk protein (casein) and sugar. Almost all participants stated that their children were on a diet of flour (wheat), milk, sugar, chocolate, seafood and micin. This is consistent with the statements of the first and second participants, as follows:

".../...yes dairy diet, wheat diet, and then diet of foods that contain high phenol.../...instant noodles.../...sweets.../...and sugar..." (P1)

".../...The diet is instant noodles, then foods that contain wheat, then chicken meat that is horeen or chicken meat now (boiler).../...eggs, then sea fish that dives less deeply is not allowed.../...milk also does not know you.../..." (P2)

The third and fourth participants also stated that the child was on a diet, as follows:

"...First from flour, second chocolate, milk, sugar, seafood especially crab, squid, shrimp then micin, noodles..." (P3)

"...sugar, flours like wheat flour, oat flour and all the flock, dairy diet too..." (P4)

In addition to the first, second, third and fourth participants, the fifth participant also stated that the child was also on a diet, as follows:

".../...so mainly wheat flour, then sugar, then milk, chocolate.. micin.../..." (P5)

The four participants who stated that autistic children need special care for 24 hours, namely they must always be supervised by parents, are in accordance with the results of Fitriani and Ambarini's (2014) brief interview with a mother with an autistic child in her research entitled the relationship between hardness and the level of parenting stress in mothers with autistic children, in which the mother said that caring for autistic children requires extra patience because when the child starts to tantrum and must be accompanied all the time, there the mother often experiences stress.

According to the Indonesian Autism Foundation (cited in Noor *et al.*, 2014) on therapy and diet for autistic children, explaining that the GFCF (*Gluten Free, Casein Free*) diet is a popular dietary method to overcome autistic symptoms. This is in accordance with Pratiwi's (2013) research entitled the relationship between gluten-free casein-free diet frequency scores and autistic behavior scores, concluding that a gluten-free casein-free diet in autistic people is very important to reduce these behavioral disorders. In addition, it is also in accordance with Danuatmaja's research (cited in Sofia, 2012), stating that many autistic children experience rapid development in socialization skills and catch up with other children after following and undergoing the GFCF diet.

4. Social support

Based on the results of the interviews that have been conducted, most participants stated that they received social support from the environment such as from the surrounding community. This is in accordance with the statements of the second and fourth participants, as follows

"...//...Yes, (the community) must support..." (P2)

"...//..What is clear is that Alhamdulillah, the surrounding community is very helpful (supportive) to me...//.." (P4)

The fifth participant also stated that she received support from the surrounding community, as follows:

"...//..yes (the community) there is support...//.." (P5)

Rachmayanti and Zulkaida's research (2011) entitled the role of parents in autistic children's therapy states that the attitude of the general public, namely a supportive and accepting living environment for children, is one of the factors that influence parents' acceptance of autistic children. This is in accordance with research conducted by Dunn (cited in Rahmawati *et al.*, 2013) which explains that social support is one mechanism to reduce the stress phenomenon of parents who have children with autism.

CONCLUSIONS AND SUGGESTIONS

Summary

The results of the discussion of the research on the phenomenon of the experience of mothers who have children with autism in SLB Negeri Jepara which has involved five participants can be summarized into four themes, namely the variety of maternal feelings, efforts to seek treatment, special care, and social support.

Advice

1. For SLB Parties

Can form a *Self Help Group* (SHG), especially in autism classes, which is a more intensive discussion group between mothers who have children with autism and autism teachers. So that mothers can share experiences and problems that are being faced regarding children, and teachers and other mothers can provide solutions to these problems, thus minimizing the level of stress experienced by mothers who have children with autism.

2. For the Community

Can accept and provide more social support to parents who have autistic children and autistic children, so that parents and children feel comfortable, do not feel isolated and differentiated in the community.

3. For the Nursing Profession

Can develop community mental nursing, so that it can provide health services or become a health consultant for families of autistic children.

4. For Future Researchers

Can conduct further research on the experiences of mothers who have children with autism by developing themes that have been discussed by previous researchers or discussing other themes that have not been discussed by researchers.

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