

## ORIGINAL ARTICLE

# A Qualitative Exploration of Mother's Experience in Caring Children With Autism

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## ABSTRACT

**Introduction:** Being a mother of autistic children is a difficult task. Autism spectrum disorder causes delays in many basic developmental areas, including learning to talk, play, and interact with others. The aim of this study is to explain mothers' experiences caring for children with autism. **Methods:** This study was narrative qualitative research. Data was gathered through semi-structured interviews with five mothers in Bandung who have autistic children aged 6 to 14. Data were analyzed by the content analysis approach. **Results:** 3 themes were identified. First time catching their children have autism, Autism parenting, Speech development before therapy. **Conclusion:** Mothers tried their best effort in caring for children with autism. Mothers play important roles in parenting and the development of their children. Another family member needs to support physically and psychologically for a mother who raises a child with autism.

**Keywords:** Autism, Experience, Mother

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## INTRODUCTION

Abnormalities in the development of brain structures and functions can cause several disorders or problems in development, one of which is a disorder that can occur in children, namely mental development disorders, such as mental retardation (MR), autism, and others (1,2). Autism is a disorder that occurs in the central nervous system, causing developmental disorders in children. One of the developmental disorders that occur is the motor aspect which causes children with autism to experience difficulties in taking care of daily activities (3,4). Autism is a disorder that occurs in developmental disorders so that it can affect children's development both cognitive, affective, and psychomotor. These disorders can affect children in communicating, behaving, social interaction, and controlling unstable emotions

Disorders experienced in children with autism can hinder the learning process, but they still have

the potential to be trained in their abilities. Verbal communication, social interaction, and creativity are all issues that autistic children face. As a result, they may struggle to grasp what they want and are not easily inspired by a desire to satisfy their parents or caregivers. They may also be unconcerned with their surroundings, immersed in the world they have built for themselves (5,6). Autistic children can still interact well socially if the aspects around them support them. Moreover, the role of mothers to support them, because getting lessons and teaching from special schools is not enough to make their social interactions good. The family is an early organization before society. The family consists of several members with different roles from one another. The family greatly influences children's communication and interactions, both interactions that exist in the home environment, as well as interactions that exist outside the home environment such as in society (7).

Families who have family members with special needs such as autism have an important role to train and build social interactions with autistic children either with family members or with the community. As a result, family support for autistic children can have an effect on the creation of social experiences with autistic children, including social interactions with family members such as dads, mothers, brothers and sisters, as well as social

interactions with other groups (8,9). Parents of autistic children may be saddened and disappointed by their child’s diagnosis, as well as ashamed of such feelings of families of young children. They could face problems with peer groups in the families with adolescents’ stage and access learning opportunities for their child at school. In addition, while studies have found that families with children with a disability face similar difficulties as other families, those challenges are also magnified (3,10).

Self-acceptance and maternal support for children with autism said that three of the four research objects have good self-acceptance at this time so that further handling of children with autism can be carried out well. On the other hand, one of the four research objects seems to be less accepting of the disorders that occur in children with autism. Another research in SLB Negeri Semarang looked at the impact of parenting on the social interactions of children with autism. As a consequence, in SLB Negeri Semarang, there is a connection between maternal parenting and social interaction of children with autism (11).

The role of parents, especially mothers, in children with autism is critical, and more information about mothers’ experiences caring for children with autism is required. The aim of this study was to explain mothers’ experiences caring for children with autism.

**MATERIALS AND METHODS**

This study was a qualitative study through semi-structured interviews. All conversations were captured

and verbatim transcribed. The phenomenological technique of an observational Colaizzi was used to obtain a detailed description of a mother’s experiences in caring for children with autism. Phenomenological research focuses on explaining participant experiences and feelings of mothers. Participants were recruited through purposive sampling in Bandung. Five mothers who have an autistic child in Bandung ages 6-14 years have participated in this study.

To assure integrity and reliability, many techniques were used. Credibility has been obtained by in-depth interviews. Reliability was achieved by independently reviewing by two co-authors using Colaizzi’s seven-step of data analysis, and the team compared the result and discussed them before consensus on code, category, sub-theme, and theme was reached.

**Ethical Clearance**

The Universitas Pendidikan Indonesia Research Ethics Committee gave their approval to this report No. 065/1534/V-2020/BPKP.

**RESULTS**

A total of five mothers enrolled in this study. Autism children age range between 6 to13 years old. Table I shows the theme and subtheme identified from participants. This study found three themes as following: (a) First time catching their children have autism, (b) Autism parenting, (c) Speech development before therapy.

**Table I: Theme and subtheme identified by interview (n=5)**

Results	Subtheme	Theme
"... the feeling was in the beginning there was rejection ..." (P2) "... actually, I also denial, yes I am supported by my family ..." (P3)	Denial	First Time Catching Their Children Have Autism
"... may be for me it is not a disaster but as a learning gift ..." (P3) "... In the end, just make it big, if it is already from Allah it's like that accept the situation ..." (P2)	Accepted	
"... apart from patience, the more detailed, for example, for children, I have to be more detailed, what about tea because I can't reveal it yet ..." (P3) "... So I thought he was normal like me ..." (P1)	Be patient and be more detailed	Autism Parenting
"... I treat my autistic child unlike autism, I consider him like a normal child ..." (P2) "... So it's not like to be given anything special, it's treated well the same as the others too ..." (P4)	Give positive suggestions	
"... give flexibility to hafidz to be pretentious if you want activities, what kind of activities are mangoes? Yes, but maybe it is different from other children of the same age who might be able to do this, but with the achievement of hafidz for me it is very extraordinary..." (P4) "... Because if he talks about it for a long time, he will also understand even though we have to do it many times, right. But after a long time, let him understand so he tea oh that's wrong. Mom, I was angry and didn't want to be friends so she thought that, right ... "(P1)	Provides freedom in carrying out activities	
"... I started to do everything from when I was asked to blow, massage his mouth, everything, then tie his tongue, what I did for one month. from there he has started to feel like he can talk until now ... "(P5)	Notified over and over when things went wrong	
"... In the past, when he was a child, how old was he, he could even call someone's name, for example, someone called him who he was following. Then if asked answer yes, if now he is usually the only one so what is it, just a few words ... "(P1)	Parents always do therapy at home as recommended by the therapist	
"... can you talk about mom and daddy like that, right, but always backwards over a year, that's 12 months back there ..." (P2)	Has decreased every year	Speech Development Before Therapy

## DISCUSSION

The experience of mothers caring for children with autism was explored in this report. We summarized three themes: First time catching their children have autism, Autism parenting, and Speech development before therapy. The mothers caring for children with autism thought that their children are as a learning gift from God.

Based on the characteristics of the respondents, the data shows that all respondents are housewives. This is because most families who spend a lot of time are mothers and those who a lot of waiting for their children at school when school hours are mothers. Mothers provide greater support than fathers, mothers feel a sense of responsibility for their child's normal-abnormal condition, care for children from the time they are in the womb, give birth to the child's growth period (12). In building family routines, mothers play a major role in coordinating occupations that can affect their health and well-being (13)

Mothers of children with autism have poorer health and well-being, as well as higher levels of depression, than mothers with children with other disabilities (14). Many mothers have indicated that their stress is connected to controlling the actions of their infant, obtaining resources, and engaging with professionals working with their child (13) The mother's struggle to retain a favorable view was made even more difficult by the views of others.

Even though at the beginning of the birth of the mother's child, she felt that she was rejecting her fate, but slowly the mother began to accept and try for the best for her child. At this point, parents discovered something wrong at various points in their child's growth and started looking for answers from health care professionals (15). Maternal support for autistic children is reflected in support in the form of instrumental support and emotional support. This instrumental support is in the form of paying attention to children, providing free time to play with children at home when at school the family accompanies the child, and the family also always takes and picks up children to school, and the family always provides nutritious food (16). Meanwhile, emotional support is in the form of support for children to feel confident, provide support, recognition, appreciation, and attention. The mother admits this is an attempt by the mother to be able to view children with autism to be the same as other normal children (16).

Parenting is described as parents' and children's attitudes and behaviors in interacting and communicating, with parenting having a significant impact on the development of children's interactions. The application of parenting styles for autistic children is in the form of Patience and more detail, giving positive suggestions, giving freedom

in doing activities, being notified repeatedly when making mistakes, and parents always doing therapy at home as recommended by the therapist. Mothers do this so that children can grow and develop optimally. Parents also received input from educators and neighbors about the growth of their children (3).

In the areas of socialization, communication, and comprehension, kids with autism can display early and serious symptoms. Their families face the difficulty of trying to recognize the condition before the diagnosis, and new challenges emerge after the diagnosis, such as dealing with it. The underlying connection with a medically introverted youngster requires revamping of family plans, which frequently causes passionate and actual over-burden for relatives, particularly the mother, bringing down the family's personal satisfaction. Family over-burden can be reduced by guaranteeing a precise and brief analysis, bringing issues to light of the problem, sharing the improvement of fitting consideration plans, and reinforcing the social encouraging group of people for kids with mental imbalance and their families (13,17,18).

Good thoughts can serve as a psychological stress buffer and can assist individuals in difficult environments to find positive significance. Reflecting on the positive experiences of parenting children with autism is likely to have physiological and psychological benefits for parents. In general, moms had more certain encounters than fathers. All the more explicitly, they found that moms recommended that their youngsters were a wellspring of solidarity and family closeness, that moms turned out to be more open minded toward things, adjusted to unchangeable things, and were more delicate to family issues, extended interpersonal organizations, and a wellspring of learning as they responded to their kids' difficulties, and that moms turned out to be more lenient toward things, adjusted to unchangeable things, and were more touchy to family issues, extended informal communities, and a wellspring of learning as they responded to their kid (19,20).

In this study, mothers also shared experiences related to children's development before doing therapy. It is stated that there is no meaningful development of their children's development, and often experience setbacks in child development. so that the mother stated that this therapy supports the development of children with autism so that they can have optimal growth and development. In addition to their therapist, mothers often received misinformation from family members who claimed that the action of their child was compatible with their family background, such as a son who delayed speech, like his father (15,21).

The mixture of experiences of both loving and embracing their child as they are and being the therapist working to support the growth and cure disability of the child

brought extra tension and demand to their everyday lives. But in this study mothers showed that they do their hardest to care for autistic children. Mothers play an important role in developing children's development. Therefore, family support is very important to enable them to mentally and materially care for their children. It is important for mothers to engage in me-time activities in order to address their health and well-being.

## CONCLUSION

The experience of mothers of autistic children begins with the first-time phase of catching their children with autism, as well as trying their best in carrying out autism parenting in developing children's development. family and therapist support are needed for mothers to carry out their roles as best as possible.

## ACKNOWLEDEMENT

The author would like to thank all the participants who have shared their experiences with the researcher.

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