

# Managing Mothers' Expectations in Caring for Autistic Children from a Nursing Perspective: A Qualitative Study

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## ABSTRACT

**Background:** Autism is a syndrome with a deviation or delays in behaviors, communication, and social interactions. Therefore, a mother needs to have an understanding of caring for a child with autism, and a nurse needs to understand the thoughts, feelings, and behaviors of parents, especially mothers, in caring for their children. This study aimed to explore the management of mothers' expectations in caring for children with autism from a nursing perspective. **Methods:** This research is a qualitative study; semi-structured, in-depth interviews were conducted with 7 participants who are parents of children with autism. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were applied to ensure rigor. Thematic analysis was used to carry out this study. **Results:** This research identified four themes and 11 sub-themes: (1) Awareness of the limitations of a child; (2) Empathy of a child's love language for problem-solving; (3) Understanding the acceptance process; and (4) Realistic expectations for the child. **Conclusion:** This study provides a detailed list of mothers' expectations for treating children with autism. Mothers have a way to manage their expectations about their child's condition. They also have great hopes for their children's future to succeed in their education and life. Nurses can provide professional nursing care to children with autism, especially in preserving the mother's mental health.

**Keywords:** *Autism Children; Caring; Mothers' Expectations*

## INTRODUCTION

Autism was identified as one of the worldwide public health concerns that challenge affected individuals and their caregivers. Autism increasingly appears on the surface after a growing number of toddlers experience this condition, according to the National Institutes of Health (NIH, 2021). The exact number of children with autism is not known precisely, but several studies have revealed no single definite cause. Several factors include genetic, immunological, metabolic, and environmental factors (Lazar *et al.*, 2024; Miranda *et al.*, 2019). The prevalence of autism is four times more common in boys than girls, according to the Centers for Disease Control and Prevention (CDC, 2024). In Indonesia, the number of people with autism is increasing. There are 2.4 million people with autism in Indonesia, an increase of 500 new patients annually (Maemonah *et al.*, 2021; Nurmalia *et al.*, 2020). The overall prevalence of Autism Spectrum Disorder (ASD) was 27.6 per 1,000 (one in 36) 8-year-old children and was 3.8 times more common among boys than girls (43.0 versus 11.4) (Walensky *et al.*, 2020). This increase has made children with autism an essential and urgent topic and study to be discussed by child health experts, developmental psychologists, and even families with children with autism.

Success in caring for children with autism is determined by the parents' or family's full support and their roles as caregivers (LaLiberte *et al.*, 2024; Viana *et al.*, 2021). It is a crucial support system for children with autism because the family is the initial environment for children to interact socially. Family support, acceptance, and attachment are psychological effects that can positively influence the growth and development of children

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with autism (Frosch, Schoppe-Sullivan & O'Banion, 2021; Kubo *et al.*, 2021). Family support for children with special needs is essential. Parents are caregivers for children with special needs, who help assist those with disabilities and in need of help because of their limitations (Moosa-Tayob & Risenga, 2022; Opoku *et al.*, 2023; Smith *et al.*, 2023). A nurse needs to understand the dynamics of caring for children with autism to be able to approach the parents, especially mothers, to care for them throughout their lives (Uddin & Ashrafun, 2023).

In Indonesia, mothers have taken on the daily responsibility and play the vital role of caring for both children and those with special needs. Mothers should accompany their children's growth and development to ensure its optimality, starting from self-control in eating, defecating, talking, walking, and socialising because it relates to their personal development. Caring for children with special needs, such as autism, is certainly different from caring for children in general (Johnson *et al.*, 2023). Therefore, it is necessary to carry out research using a phenomenological approach through in-depth interviews about managing mothers' expectations in caring for children with autism from a nursing perspective.

## METHODOLOGY

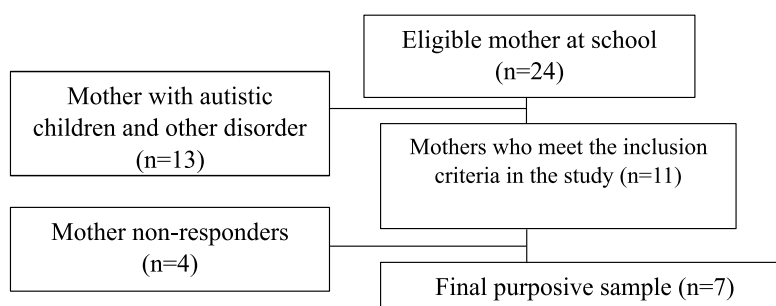
### Study Design

The method used a qualitative study with a descriptive phenomenological approach. Phenomenological studies to thoroughly explore individual life experiences are optimally possible with a relatively small number of samples (Lewis, 2018). The study allowed for in-depth interviews about managing parents' expectations of their children with autism. The study was conducted following the COREQ.

### Setting and Participants

This study's population is mothers of children with autism. The total number of samples in this study is 7 participants until it reaches data saturation. The participants in this study are parents who care for children with autism at the YKDW Special School and are selected based on the inclusion criteria. The selection of participants for this study uses a purposive sampling method, which is based on specific intentions or goals determined by the researcher (Renjith *et al.*, 2021).

Inclusion is a characteristic that needs to be fulfilled by every member of the population to be taken as the research sample (Gill, 2020). The inclusion criteria in this study were (1) parents who have children with autism registered as students at the YKDW Special School, Tangerang City, and (2) willing to take part in research from start to finish. The exclusion criteria in this study were mothers who have children with autism and other disorders.



**Figure 1: Recruitment Flowchart**

Figure 1 visually explains the step-by-step selection and refinement process of participants, showing process of the research moved from a larger initial pool to a smaller, purposive final sample for the study.

### Data Collection

The questions in the instrument are arranged based on the research objectives that have used validity testing. The question guide consists of several questions: (a) "What makes the mother believe that her child has autism?"; (b) "How does the mother feel after finding out that her child has autism?"; (c) "What did the mother do first after discovering her child has autism?"; (d) "How does the mother handle her child when they are being

aggressive?"; "How does the mother handle a child who is unfocused?"; and (e) "What are the mother's experiences in caring for an autistic child to become independent in daily life activities?".

The data collection process begins with explaining the research and ensuring the participants have filled out informed consent. The interviews in this study were conducted using semi-structured in-depth interviews. In-depth interviews by face-to-face were conducted by researchers for 30-40 minutes for each participant and were conducted in 2020. The interviews were recorded using a smartphone and field notes to record participants' responses—using Indonesian in a quiet classroom setting, and no one else was present. Data collection ceased at saturation when the participants had no new perspective.

The interview implemented pandemic protocols, including maintaining about 1 (one) meter between the researcher and the interviewee, wearing a mask, and implementing coughing and sneezing etiquette. During the interview, the researcher used therapeutic communication and interview guidelines. The interview guide has been expert-tested by nursing experts, and one of the researchers is an expert in psychiatric nursing.

**Data Analyse**

The data analysis technique used in this study was the phenomenological method developed by Colaizzi, where the data analysis process was carried out simultaneously with the data collection process (Praveena & Sasikumar, 2021). The Colaizzi analysis method consists of seven stages, which include (1) Reading the interview transcripts repeatedly and giving marks to see the correspondence between the recordings and the field notes and gaining comprehensive knowledge about the phenomenon being studied, (2) Reviewing the results of the interview transcript then code the statements that are significant or fit the purpose and enter them into the data analysis table by using computerisation, (3) Formulating the meaning of each statement so that the essence is found, (4) Organising the meanings that have been formulated into theme groups, (5) Integrating the themes obtained into a saturated form of description of the phenomenon being studied, (6) Carrying out validation by asking participants to read the themes obtained by adjusting their experiences and gave comment or correction, and (7) Refining the results of data analysis based on previous validity results. Numeric codes were used instead of real names to ensure the confidentiality of the participants' information.

**Reliability and Validity**

This study considers credibility, dependability, confirmability, and transferability to ensure trustworthiness. Regarding credibility, the researcher conducts member checks regarding the results of data analysis. For dependability, the researcher carries out structured data coding processes and accurately interprets the study's findings regarding confirmability and interpretations considering previous research results. The researcher ensures sample variation according to inclusion criteria to achieve generalisation regarding transferability.

**Ethical Consideration**

The researchers obtained ethical clearance from the Muhammadiyah University of Jakarta, Indonesia with reference number 011/PE/KE/FKK-UMJ/VII/2020 on 14<sup>th</sup> July 2020.

**RESULTS**

**Demographics**

*Table 1: Identity of Mothers and Children*

Participants	Age of the Mothers (years)	Age of the Child at Diagnosis (years)	The Current Age of the Child (years)
P1	46	1	12
P2	48	4	9
P3	32	3	7
P4	32	2	10
P5	32	3	10
P6	39	2	14
P7	35	3	9

The researcher conducted interviews with each participant. The interview took place in the participant's house while health protocols were also implemented. A total of seven participants were voluntarily involved in the study with the above characteristics mentioned in Table 1.

**Table 2: Thematic Tree (The Main Themes and Subthemes of Mothers' Expectations in Caring for Children with Autism from a Nursing Perspective)**

Themes	Sub-Themes
Awareness of the limitations of a child	<ul style="list-style-type: none"> <li>• Limitations in communication</li> <li>• Emotional limitations</li> <li>• Limitations in social interaction</li> <li>• Limitations of daily activities</li> </ul>
Empathy of a child's love language for problem-solving	<ul style="list-style-type: none"> <li>• Act to service medical or non-medical treatment</li> <li>• Physical touch</li> </ul>
Understanding the acceptance process	<ul style="list-style-type: none"> <li>• Recognising feelings of sadness</li> <li>• Identifying moments of bargaining</li> <li>• Remembering the time of acceptance</li> </ul>
Realistic expectations for the child	<ul style="list-style-type: none"> <li>• Being able to be independent</li> <li>• Being able to socialise</li> <li>• Being able to work</li> </ul>

**Themes**

Table 2 explains four themes and 12 subthemes were identified from the participants' experiences (Table 2). Table 2 describes awareness of a child's limitations, which include communication limitations, emotional limitations, social interaction limitations, and limitations in performing daily activities. The results of this study highlight the presence of empathy in understanding a child's language of love for problem-solving, which encompasses acts of service in medical or non-medical treatments and physical touch. This study also reveals that mothers understand the acceptance process, including recognising feelings of sadness, identifying moments of bargaining, and recalling the time of acceptance. Also, mothers have realistic expectations for their children, such as achieving independence, socialising, and working.

**Awareness of the Limitations of a Child**

**Subtheme 1: Limitations in communication**

Children with autism have limitations in communicating because they cannot yet speak. The lack of ability to communicate causes them to remain silent. This finding is in line with the statement from one of the participants: *“Yes, he doesn't want to talk, so he just stays quiet”* (P2).

**Subtheme 2: Emotional limitations**

Participants said that children with autism also experience emotional deviations and hurt themselves. This statement is supported by one of the participants: *“Yeah, we would ask him to play games with us because if he did not get what he wanted, he would cry in the middle of a crowd (stares at An. K).”* (P1).

**Subtheme 3: Limitations in social interaction**

Children with autism experience limitations in social interaction with others. Other symptoms were identified in other participants, which indicated that there were limited interactions where children had difficulty focusing on face-to-face contact. According to the participant, *“When the family comes for a visit, he prefers to be alone. He just would find another place to isolate himself.”* (P2).

**Subtheme 4: Limitations of daily activities**

Children with autism who are still in the process of their development period have difficulties because physical characteristics strongly influence childhood. According to participant statements: *“We will put the shampoo on his head for the shower and give him a soap and a scoop, but when it seems like there is not enough water, we will give him some more water if he does not rinse it well. Sometimes, it is still not clean.”* (P7).

## **Empathy of a Child's love Language for Problem-Solving**

### **Subtheme 1: Act to service medical or non-medical treatment**

In this study, participants revealed how to solve problems that mothers do, which is seeking treatment for their children with autism. Participants sought information about autism by asking experts such as doctors or psychologists; the following is the participant's statement: *"It's good to ask the doctor whether there should be a special diet or something as such"* (P3).

### **Subtheme 2: Physical touch**

The results of the study found that the resolution of mothers in dealing with children with autism is more the actions of mothers toward their children; when children act up, mothers tend to treat children by hugging them because, according to mothers who take care of children with autism, that treatment is more effective in calming children's emotions. The following is the participant's statement: *"Yes, I hugged him from behind his hand, I held it, I held it, so I crossed it in front of his body, and then I also pressed his feet until he calmed down."* (P6).

## **Understanding the Acceptance Process**

### **Subtheme 1: Recognising feelings of sadness**

The research results obtained by the participants showed various reactions when they found out their child was diagnosed with autism. The participant's statement is as follows: *"Yes, it's a little sad, but because I already know I have a problem for a year, I'm also relieved. "Oh, autism."* (P6).

### **Subtheme 2: Identifying moments of bargaining**

Every mother experiences the process of taking the existence of a child. Mothers share this process with feelings. Mothers are still convinced of themselves. The presence of their child feels like it is their fault. They talk to themselves. The following is the participant's statement: *"I even talked to myself, is my child really autistic."* (P5).

### **Subtheme 3: Remembering the time of acceptance**

According to the participant's statement: *"What can I say (laughs), maybe it's predestined, so you have to accept it. It's been entrusted by Allah"* (P1).

## **Realistic Expectations for the Child**

### **Subtheme 1: Being able to be independent**

The study results show that children with autism are very dependent on other people, especially their mothers. One participant mentioned: *"Hmm, regarding academic development, I think the child is not independent enough to read and write on their own."* (P6).

### **Subtheme 2: Being able to socialise**

Apart from being independent, mothers who have children with autism expect their children to be able to socialise; this is confirmed by one of the participant's statements: *"Yes, hopefully, he can socialise in public schools like other children (teary-eyed)"* (P3).

### **Subtheme 3: Being able to work**

Mothers hope that their children choose to work to open their businesses when they graduate from academics. Following the statement of one participant who said: *"I hope that when you graduate from school, but later, for example, if he can't work at a factory because he can't communicate with the others."* (P7).

## **DISCUSSION**

### **Awareness of the Limitations of a Child**

The characteristics of limitations in communication, emotion, social, and daily activities are early signs of

autism detected by mothers. All participants said that children with autism experience delays in communication, which is marked by the child being unable to speak. At two years old, the child was unable to talk. Language and communication are essential as a complex part integrated into the interaction system between children's and parents' communication (LaLiberte *et al.*, 2024; Senouci, Hussein Obeidat & Rabha Gaouti, 2021). Three participants expressed emotional deviation, who said their child sometimes cried, broke things, and even hurt themselves. The emotions of children with autism look like anger, laughter, and crying for no reason (Lecciso *et al.*, 2021; Liang *et al.*, 2024). If their wish is prohibited, autistic children can damage objects around them by banging their heads against the wall.

The problems can be found in several disorders dominantly, including communication disorders, slowness in language or inability to communicate, disturbances in social interaction, lack of eye contact, doing activities constantly repeated, facial expressions un-matching their behaviors, moving without knowing the direction, and often found activities that could hurt themselves (Doaee, Ghomeishi & Sotoudeh, 2024; Flenik *et al.*, 2022; Lazar, Challman & Myers, 2024; Lecciso *et al.*, 2021; Lindor *et al.*, 2019). Parents must be responsive and need training to help and treat their children.

Children did not want to be friends and preferred to be alone. During the COVID-19 pandemic, autistic children tend to be disturbed in social interaction. They were not interested in playing with friends, chose to be alone, and avoided eye contact (Mujahid, 2022). Autistic children also behave indifferently toward others (Silveira-Zaldivar, Özerk & Özerk, 2020). Social interaction, such as social relationships with their environment, is a real difficulty for children with autism. Limitations in children with autism can prevent them from having abilities or making social relationships (Lindor *et al.*, 2019). Humans always need the togetherness of other people, and so do children with special needs; they all need to establish satisfying social relations with the environment (Frye, 2018).

Participants expressed that the ability to accomplish daily activities was limited, so children could not carry out personal hygiene independently. Sometimes, mothers give them certain body gestures as an example when their children are unable to perform a task properly. Toileting activities such as bathing, dressing, and decorating are challenging for school-age children with autism (Cañete *et al.*, 2024; Kruger, Silveira & Marques, 2019). Each child with autism has different motor stimuli. Children with autism experience a decrease in sensory-motor abilities and daily living skills, resulting in a deficit of sensory and motor abilities in children, which impacts the independence of children with autism in completing everyday activities (Monteiro *et al.*, 2022).

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Mothers will encounter many unexpected things in raising children with autism. However, mothers often experience difficulties understanding children's wishes because they cannot be sensitive to their expressions and behaviors. In the present study, participants experienced limitations in sensitivity to children's wishes when children asked for something. The participants revealed that their children tended to pull their mothers' hands and point when they wanted something. Parents are often confused about what their children want during the COVID-19 lockdown (Tokatly Latzer, Leitner & Karnieli-Miller, 2021). The speech abilities of children with autism accompanied by language disorders were still low, so they still used body signals and pulled their hands when they wanted something (Broome *et al.*, 2021; LaLiberte *et al.*, 2024). In addition, every parent responds differently to the wishes of children with autism (Crowell, Keluskar & Gorecki, 2019). Because the children experience failure and obstacles in explaining to their mothers what they want, while the mother's knowledge about autistic children is lacking and the child's condition makes it difficult to communicate, parents are limited in understanding their child's wishes.

## Providing Empathy for a Child's Love Language for Problem-Solving

The second theme is understanding a child's love language, which is the effort that helps a person handle situations to solve problems (Al-Oran *et al.*, 2022). Based on the issues experienced by all mothers, various ways and efforts are chosen by someone to overcome the problem. Seven mothers used act-to-service strategies when they found out that their child had an abnormality in growth and development. Mothers took their children to the doctor and even consulted with a psychologist first. One participant got information about autism through television and the internet. In addition, all participants also said that they were trying to provide the best therapy. The treatment for each child was different—mothers make a series of efforts to overcome the problems, such as visiting experts and seeking information related to children with autism by watching television, reading books, and searching on the internet (Cañete *et al.*, 2024; Doaee, Ghomeishi & Sotoudeh, 2024; LaLiberte *et al.*, 2024).

Participants explain that sometimes showing emotions towards their children with autism can work as a physical touch strategy in the form of self-control. This strategy can be done by hugging them or keeping silent. Individuals regulate feelings or actions related to existing problems (Davico *et al.*, 2022). Having children with autism encourages mothers to come up with solutions to overcome their problems and avoid stressful conditions (Vernhet *et al.*, 2019). Providing empathy for a child's love language will be used in the form of problem-solving strategies and emotional ones. Understanding the child's love language is an effort for mothers to help their children grow and develop like other children.

## Understanding the Acceptance Process

Every mother has hopes for their children; mothers always have realistic expectations for the good and success of their children. Mothers hope that their children can be independent. The interviews with participants revealed that mothers still assisted in bathing, and even children were still assisted in defecating. Children were less capable of independence and still depended on their mothers in terms of wearing clothes, eating, bathing, and urinating (Acharya & Sharma, 2021; Liang *et al.*, 2024; Smith *et al.*, 2023). In the second category, mothers hope that children can socialise. They hoped their children could socialise in public schools like normal children. The participants also want to see their children socialise alone. Social relations are relationships between humans who need each other; social relations start from a simple and limited level based on superficial needs (Cogzell, 2018; Laily Hidayati & Noor Aisha, 2022). At a more mature and increasing age, human needs become more complex; thus, social relations develop very complexly.

## Realistic Expectations for the Child

Mothers hope their children can acquire a job, but seeing their children's limitations, mothers prefer their children to establish their businesses. Mothers' expectations for their children are very high because children are the family's future, which means that children are the family's hope (Kubo *et al.*, 2021; LaLiberte *et al.*, 2024; Opoku *et al.*, 2023; Reupert *et al.*, 2022; Smith *et al.*, 2023). Every parent wants their child to be born healthy, bright, and normal like any other child. Mothers expect their children to succeed in their education and life. Furthermore, as a nurse, special training is needed to be able to care for children with autism and understand the mother who has cared for them since birth.

## Limitation

This study had a few limitations, including a small sample size and being conducted in a single special school. Additionally, the focus on mothers of children with autism did not fully explore the role of both parents. Despite these limitations, the study contributes to understanding the unique experiences of mothers of children with autism and emphasises the need for further investigation into the role of both parents. It lays the foundation for future research that could offer more comprehensive insights into the topic across diverse populations and settings.

## CONCLUSION

From the present study it is evident that the meaning of mothers' experience in caring for children with autism from a nursing perspective is that each mother reveals that characteristics such as limitations in communication, emotions, and social and daily activities are the early signs of autism that mothers notice.

However, mothers have strategies for dealing with problems despite their constraints in understanding children's wishes. With autism, mothers have a way of accepting their child's condition and have great hopes for their child's future. Therefore, this study highlights the significant challenges faced by mothers of children with autism, particularly in communication, social interactions, and daily living skills. It underscores the importance of early intervention, individualised therapies, and providing emotional and practical support for both the children and their parents. By addressing these needs, the development and quality of life for children with autism can be enhanced, fostering their independence and social integration, while also empowering parents with the knowledge and resources needed to support their children effectively.

### **Recommendation**

Early intervention programs and support for parents of children with autism should be prioritised to address communication, emotional, and social challenges, providing training and counseling to reduce stress. Appropriate therapies and specific treatment plans should be developed in collaboration with healthcare professionals to meet the unique needs of each child, especially in motor skills, communication, and daily activities. Programs promoting socialisation and independence should be implemented to enhance the development of life skills, helping children with autism build relationships and integrate better into society. In addition, the role of nurses needs to be explored more deeply, especially in caring for children with autism. The scope of nursing research in the future can be psychiatric nursing or pediatric nursing, especially for children with special needs (autistic children).

### **Conflict of Interest**

The authors declare that they have no competing interests.

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