

## portrait Quality of Life of a Mother Raising a Child with Autism

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Abstract: This study aims to explore what life is like for a mother raising a child with autism. A mother's quality of life in this situation is shaped by four main aspects: physical health, psychological well-being, social relationships, and the environment. The research used a qualitative case study design with one participant—a mother of a 4.5-year-old child with autism. Data were collected through in-depth interviews and direct observation. The results show that the mother experienced many challenges in these aspects, such as feeling physically exhausted from lack of sleep, emotional stress, and financial struggles in paying for her child's therapy. On the other hand, family support, acceptance of the child's condition, and a supportive environment—like access to good special school facilities—helped her improve her quality of life. This study is expected to give useful insights for strengthening support systems for mothers raising children with autism so that their lives can become healthier and more balanced.

### 1 INTRODUCTION

Autism is a developmental disorder in children, mainly marked by difficulties in communication and social interaction (Indriastuti, 2019). In the 1960s, the global prevalence of autism was only about 0.04%. Over the years, this number has steadily increased to 0.62–0.70% (National Center of Biotechnology Information, 2012). In the United States, one out of every sixty children is diagnosed with autism, while in South Korea the prevalence reaches 2.6%. In Indonesia, the numbers are estimated to be quite similar since autism is not influenced by ethnicity or economic level (Fauzy & Fourianalistyawati, 2017).

The American Psychiatric Association (2018) explained that children with autism often show early developmental delays, especially in language and communication. These difficulties do not only affect

the children themselves but also their parents—particularly mothers. Mothers raising children with autism are reported to have higher levels of stress compared to parents of children with other developmental challenges (Ikhwanisfa et al., 2024). In addition, mothers of children with autism often face unique behaviors and characteristics, making them more vulnerable to mental health issues, physical problems, and lower quality of life. Around 40% of these mother's experience depression (Coyle, 2009).

When a mother first learns that her child has autism, her initial reaction is usually disappointment, sadness, anger, or denial (Mansell & Morris, 2004). Caring for and raising a child with autism often leaves mothers with little time to rest, which then affects their physical health. Problems like back pain, headaches, and sleep issues are common (Kuhlthau et al., 2014). Financially, mothers must also prepare for

the costs of therapies and inclusive education for their children (Rapin, 2013). All of these factors make mothers of children with autism highly vulnerable to a lower quality of life.

Conceptually, quality of life is defined as how a person perceives their position in life, which is shaped by their expectations, goals, worries, and standards (WHO, 2022). Quality of life is influenced by health, social support, and the strength of one's support system (Supriani, 2021). A good quality of life for mothers brings happiness and psychological well-being, while prolonged stress, fatigue, and health problems can significantly reduce it (Audina Sitorus & Patria Saroinsong, 2023). This shows the importance of giving special attention to improving the quality of life for mothers of children with autism.

The Centre for Health Promotion (CHP) describes quality of life as how people function in their daily activities. The World Health Organization (WHO) identifies four main dimensions of quality of life: physical health, psychological well-being, social relationships, and the environment. These dimensions are interrelated, and understanding them is important for helping mothers improve their lives while raising children with autism.

According to WHOQOL (2021), each dimension has its own indicators. For example, physical health indicators include sleep and rest, pain, and dependence on medication. Psychological indicators cover positive and negative feelings, self-image, and concentration. Social relationship indicators include social support and personal connections. Environmental indicators include financial resources, safety, access to public facilities, and healthcare. Many studies use this framework to

examine the quality of life of mothers of children with autism in different contexts.

Previous studies found various factors that influence mothers' quality of life. Mothers who lack psychological support from their families or who constantly worry about their children's future often experience declines in psychological and social aspects of life (Pertiwi & Irwanto, 2020). Stress in caregiving also negatively correlates with quality of life (Ahmed et al., 2023). Similarly, Rezaq, Albalawi, & Alharbi (2025) found that low social support and financial difficulties significantly reduce mothers' quality of life.

While previous studies have examined stress and social support, few have looked deeply into the quality of life itself—especially in terms of physical health and environmental conditions (Ahmed et al., 2023). This leaves a gap in understanding that needs to be filled with further studies.

Based on this, the present study aims to explore how a mother raising a child with autism perceives her quality of life. Every mother may define "quality of life" differently, depending on how she views her circumstances (WHO, 2022). Having a child with autism often brings changes to a mother's life—physically, psychologically, socially, and environmentally (Awaji et al., 2021). Therefore, by exploring these experiences, this study hopes to provide support and deeper understanding that can help improve mothers' quality of life.

Maintaining mothers' quality of life is crucial. If it declines, the impact can be serious, including chronic fatigue, prolonged stress, or even depression. This, in turn, can affect the child's growth and development. For this reason, this study seeks to provide a deeper understanding of the factors that

influence the quality of life of mothers raising children with autism.

## 2 METHOD

### Participants

The participant in this study was chosen using purposive sampling. She is a 45-year-old mother living in Blera who has a 4.5-year-old child with autism, currently enrolled at Ceria Mandiri Special School (SLB) in Blera. This participant was considered suitable because she fits the criteria of being a mother raising a child with autism. Her presence gave the researcher rich and meaningful insights into what her quality of life is like while caring for her child.

### Design

This study used a qualitative design with a phenomenological approach. This approach was chosen to dig deeper into the subjective experiences of mothers raising children with autism. It allowed the researcher to understand the meaning of “quality of life” from the participant’s own perspective. Through this approach, the researcher could also capture how the mother felt and coped with her child’s condition. Data were collected through in-depth interviews and direct observation.

### Procedure

The procedure began with conducting an in-depth interview with the participant. The interview took place at Ceria Mandiri SLB and lasted for about one hour. In addition to the interview, the researcher also observed the participant during the session. The interview data were then transcribed into verbatim

form and organized into a findings table. From this table, themes were developed, interpreted, and summarized into conclusions

## 3 RESULT

From the interview with the participant, the researcher found that her quality of life can be described through four main dimensions: Physical health, Psychological well-being, social relationships, and environment.

Table 1 Summary of Results

Dimension	Theme	Sub-themes
Physical Health	tired from taking child to therapy	Long distance to therapy place makes her physically drained
	Lack of sleep because of child	Frequent tantrums, high energy both day and night
	Fever and headaches	Felt unwell and sick due to lack of rest
Psychological	Anger: “Why my child?”	Shock, sadness, anger, questioning why this happened
	Self-reflection during pregnancy	Regret about taking medicine early in pregnancy
	Praying to stay strong	Asking God for strength and patience
Social Relationships	Ignoring stigma	Chooses not to respond to negative comments
	Supportive relatives	Family understands her situation
	Husband helps with childcare	Husband shares the responsibility
Environment	Supportive school facilities	SLB provides good facilities for the child’s growth

RecoHigh therapy costs	Financial struggles to cover monthly expenses
Child adapting to environment	Hope that the child adjusts well during therapy

### Theme 1: Tired from Taking Child to Therapy

The participant explained that the therapy center was quite far from her home, which made her feel physically exhausted. Sometimes she even felt reluctant to go, but she pushed herself for the sake of her child's future.

“Sometimes I feel really tired when I have to take him to therapy. The place is about 8 km from our house. There were times I felt so lazy to go, but I held on—for my child's future.” (participant cried while telling this story)

### Theme 2: Lack of Sleep Because of Child

The participant shared that her child often experienced long tantrums, sometimes late at night. When the child refused medication, he would run out of the house with very high energy, leaving her sleepless and constantly alert.

“I lost so much sleep. Once, at night, he refused to take his medicine, and instead he ran out of the house all the way to his grandma's place across the street. It lasted until midnight.”

### Theme 3: Fever and Headaches

Trying to balance childcare and financial needs, the participant once ran a small shop while also taking her child to therapy. The constant lack of rest made her sick with fever and frequent headaches.

“I once got so sick with fever and chills because I was exhausted. I even had to take medicine. I used to run a small snack shop to help financially, but now I fully focus on my child. I also often feel terrible headaches.”  
(participant cried)

### Theme 4: Anger – “Why My Child?”

When she first learned about her child's diagnosis, the participant felt angry, sad, and in denial. She sometimes questioned what sins she had committed to deserve such a trial. Her husband also felt shocked, and her other children sometimes felt jealous of the attention given to their autistic sibling.

“I was shocked, angry, sad, and confused. I asked myself why my child had to be like this. Even my husband was sad, and my other kids sometimes complained that I paid more attention to their brother.”

### Theme 5: Self-reflection During Pregnancy

The participant shared feelings of guilt related to her pregnancy. She initially did not realize she was pregnant, took medicine, and even admitted that she was reluctant to have another child at her age. Later, she interpreted her child's condition as a test from God.

“Back then, I didn't want another child because I was getting older and already had many kids. I didn't realize I was pregnant and even took medicine when I thought I was just sick. I found out I was four weeks pregnant. After giving birth, I wasn't that happy at first. I feel maybe this is God's way of reminding me.”

### Theme 6: Praying to Stay Strong

She often turns to prayer, asking God to give her and her family strength. She also tells her husband not to worry too much and encourages her other children to be more understanding toward their autistic sibling.

“I can only cry and pray, asking God for strength. I remind my husband not to worry too much so he can focus on work, and I tell my older kids that I'm not being unfair— their brother just needs special care.”

**Theme 7: Ignoring Stigma**

The participant chooses to ignore the negative comments from neighbors, believing that everyone has their own struggles.

“I just ignore it. People don’t know what it’s like unless they’re in my shoes. Everyone has their own tests in life, so I don’t need to care about gossip.”

**Theme 8: Supportive Relatives**

She feels grateful for supportive relatives. Her mother, mother-in-law, and even her older children eventually accepted and cared for their autistic sibling. Her husband, though sometimes still upset, has also grown calmer over time.

“Thank God, my relatives are kind, my mother and mother-in-law never blamed me, and my older kids now care for their brother. Even my husband, although he sometimes gets upset, is calmer now. I feel more at peace.”

**Theme 9: Husband Helps with Childcare**

Her husband often helps care for their child, even staying up late during tantrums. Despite his demanding work, he tries to come home early and share responsibilities, though sometimes he still struggles with feelings of embarrassment.

“Thank God, my husband helps too, even when he’s tired. He sometimes comes home early even if he was working out of town. Of course, sometimes he gets frustrated, but he really helps.”

**Theme 10: Supportive School Facilities**

The participant appreciates the facilities at Ceria Mandiri SLB. She finds the services professional, with good teachers, therapies, and even diet management. This makes her feel grateful for the environment.

“The SLB really helps. The facilities and teachers are great, and the therapies and diet plans are well managed. It really supports my child’s growth.”

**Theme 11: High Therapy Costs**

Financial struggle is one of her biggest burdens. The cost of therapy and school is high, and since she is unemployed, she sometimes has to cut her other child’s allowance or look for cheaper alternatives.

“Money is the biggest issue. Therapy and SLB are expensive. I sometimes send my other child less pocket money, and I even tried using massage therapy as a cheaper alternative.”

**Theme 12: Child Adapting to Environment**

Her biggest hope is that her child can adapt well to his surroundings, communicate better, and live independently in the future.

“I really hope my child can communicate better and adapt to the environment. I feel guilty sometimes, so I just want him to live happily.”

**4 DISCUSSION**

This study shows that the quality of life of a mother raising a child with autism is influenced by four key dimensions: (1) physical health, (2) psychological well-being, (3) social relationships, and (4) the environment. These dimensions are interconnected, and challenges in one area can affect the others. Mothers of children with autism are especially vulnerable to both physical exhaustion and emotional strain. This aligns with previous studies that reported mothers of autistic children often experience chronic stress and health problems. In fact, about 40% of them suffer from depression (Chodidjah & Kusumasari, 2018).

The emotional stress described by the participant—such as anger, sadness, and initial denial after hearing the diagnosis—matches the findings of Ikhwanisfa et al. (2024), who found that prolonged

emotional stress among mothers affects their overall quality of life. Continuous stress drains energy and disrupts daily functioning, making psychological well-being a crucial factor in mothers' quality of life.

Still, not all mothers experience emotional stress in the same way. While the participant in this study initially reacted with anger and sadness, she eventually engaged in self-reflection and tried her best to accept and care for her child. This supports the idea of Sari et al. (2011), who explained that mothers' past experiences and perceptions can shape their current quality of life. In this case, feelings of guilt from pregnancy also added weight to the mother's psychological burden. Too much self-blame may worsen psychological well-being.

At the same time, prayer and hope emerged as important coping strategies. The participant repeatedly prayed for strength for herself and her family. Hope and faith helped her transform exhaustion into motivation. Kuhlthau et al. (2014) also highlighted that prayer and hope can improve parents' quality of life, especially when caring for children with special needs.

The participant also showed persistence in managing practical challenges. Despite the long distance and her own fatigue, she consistently took her child to therapy. She also worked on controlling her emotions when dealing with tantrums. These strategies are in line with Armajayanthi et al. (2017), who found that mothers of autistic children often develop coping strategies to protect their psychological well-being.

Support from a spouse is another key factor. The participant's husband helped with childcare despite his own workload. This echoes Pisula & Kossakowska (2010), who found that supportive

partners reduce maternal stress and improve life satisfaction. Emotional and practical support from a husband can make a significant difference, as seen in this study.

Social stigma is another challenge. Mothers often face negative comments from neighbors or the community. However, the participant chose to ignore them, which helped her stay emotionally stable. This coping approach resonates with findings from Audina Sitorus & Patria Saroinsong (2023), who reported that resilience against stigma contributes to mothers' well-being.

Environmental conditions also play a huge role. A supportive school environment like the SLB Ceria Mandiri was vital for this mother, consistent with Suwijik & A'yun (2022). Conversely, an unsupportive environment could worsen her situation.

Financial struggles were another major factor. Monthly therapy costs weighed heavily on the family, forcing the participant to cut other expenses or look for alternatives. Similar findings were reported by Attinger & Wolcott (2012), who linked financial limitations with increased stress and reduced quality of life among mothers of children with autism.

Finally, rest and recovery are often compromised for mothers raising autistic children. Lack of sleep due to tantrums or night-time challenges directly affects health and quality of life. Fauzy & Fourianalistyawati (2017) also noted that mothers with enough rest have significantly better well-being.

Overall, family support plays a central role. For the participant in this study, her husband's help and her relatives' understanding gave her strength and comfort. This supports Mirza (2017), who

emphasized that family support enhances mothers' quality of life.

Quality of life will always differ among mothers, depending on their level of acceptance. Leung & Li-Tsang (2003) found that mothers who accept their child's condition tend to have better quality of life. Similarly, Rapin (2013) argued that acceptance and self-reflection can help mothers adapt positively. The participant in this study showed this process of acceptance, moving from anger and guilt to resilience and hope.

## 5 CONCLUSIONS

The findings show that when the participant first learned about her child's diagnosis, her quality of life declined. This was reflected in her anger, prolonged stress, and feelings of denial. Over time, as she began to accept her child's condition, her quality of life improved. This improvement was supported by a positive school environment at the special school and her husband's involvement in childcare.

**Suggestions:** For future research, it is suggested to pay more attention to personal characteristics—such as the mother's personality—to give a clearer picture of how mothers interpret their experiences in raising and caring for their children. It would also be helpful for future studies to consider the child's age, to compare whether the child's developmental stage has an impact on the mother's quality of life.

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