

## How Mothers of Children With Autism Spectrum Disorder Think About Their Quality of Life?

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### Abstract

Raising a child with autism spectrum disorder (ASD) can be challenging for mothers in many ways, their quality of life: social, physical, psychological, etc. This research explored how mothers with ASD perceive their quality of life and what influences those perceptions. This study employed qualitative research design. A total of 3 mothers were participated, using convenience sampling method in Bandung, West Java. This study using a semi-structured interview with a prepared guideline by the researchers, based on strong framework and theory. A method called content analysis was used to systematically understand the challenges they faced, the coping mechanisms they developed, and finally, the factors they believed would improve their quality of life. The data were analyzed using the content analysis approach. The participants reported a variety of difficulties and their way of coping with the problems, following factors that could help them to raise their quality of life. Results reported into 5 themes, following with 13 sub-themes. The main themes included “challenges”, “fears about the future”, “changes in social interactions”, “happiness & gratitude” and “factors to improve QOL”.

**Keyword :** autism spectrum disorder, caregiver, quality of life

### Abstrak

Hidup berdampingan dengan anak autism spectrum disorder (ASD) dapat memberikan beberapa dampak negatif pada orang tua termasuk kualitas hidup mereka yang terdiri atas aspek sosial, fisik, psikologis, dll. Penelitian ini bertujuan untuk mengidentifikasi persepsi orang tua terkait kualitas hidup yang dimiliki serta hal yang melatarbelakanginya. Penelitian ini menggunakan desain penelitian kualitatif dan teknik convenience sampling. Sebanyak 3 orang tua dari Bandung, Jawa Barat berpartisipasi dalam penelitian ini. Guna mengumpulkan data, penelitian ini menggunakan semi-structured interview dengan panduan yang telah disusun berdasarkan teori. Selanjutnya, data di analisis menggunakan pendekatan content analysis. Hasilnya diperoleh bahwa Ibu merasakan beberapa kesulitan dan upaya menghadapinya diikuti dengan beberapa faktor yang dapat membantu Ibu meningkatkan kualitas hidupnya. Hasil dari penelitian ini dikelompokkan kedalam 5 tema utama, diikuti dengan 13 sub-tema. Tema utama terdiri atas “tantangan”, “ketakutan tentang masa depan”, “perubahan dalam interaksi sosial”, “kebahagiaan & rasa syukur” dan “faktor untuk meningkatkan QOL”.

**Kata Kunci :** autism, kualitas hidup, pengasuh

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## BACKGROUND

Autism Spectrum Disorder (ASD) is a complex neurological condition characterized by significant impairments in social interaction and communication. Individuals with ASD often experience challenges in navigating social contexts, understanding nonverbal cues, and engaging in reciprocal interactions (Strock, 2007). The diagnosis encompasses a range of core symptoms, including restricted interests and repetitive behaviors, alongside difficulties adapting to changes in routine (Couturier et al., 2005). Research suggests that children with ASD may exhibit additional challenges such as frequent tantrums, sleep disturbances, and poorer overall health compared to typically developing peers (Gurney et al., 2006).

Reports suggest a rise in autism spectrum disorder (ASD) diagnoses in Indonesia. Although official statistics are scarce, estimates from the Ministry of Health suggest that approximately 112,000 children aged 5-19 have ASD (2010). However, a 2018 report from Bekasi city alone identified over 6,300 cases in children aged 0-14, indicating a potential national underestimation of ASD prevalence. Interestingly, diagnoses appear more frequent in urban areas like Jakarta, Bogor, Depok, Tangerang, and Bekasi (Jabodetabek), potentially linked to the rapid urbanization that occurred in these regions between 1970-1980 (Alsa et al., 2021). Caregivers of children with ASD often hold high aspirations for their children's futures, including independence, higher education, employment, and marriage (Lestari et al., 2020). However, such aspirations can create significant burdens for the caregivers themselves.

Pinpointing the exact prevalence of diagnosed ASD in Indonesia remains a challenge. While the Indonesian Central Statistics Agency (BPS) incorporates a category for mental disabilities within its annual population surveys, this category does not differentiate between specific diagnoses such as ASD. Obtaining a precise estimate of the current prevalence of diagnosed ASD in Indonesia remains elusive. While the 2009 Mental Disability category within the Indonesian Central Statistics Agency (BPS) survey identified 181,202 individuals, this is widely considered an underestimation. The sole published data specific to ASD prevalence dates back to 1992, suggesting a rate of 1 in 833 children (Wignyo Sumarto et al., 1992). The absence of subsequent studies underscores the significant knowledge gap. Extrapolating from a neighboring nation, Australia, where 0.5% of the population has received an ASD diagnosis (Australian Bureau of Statistics, 2012), an estimated 1,249,500 Indonesians could potentially be on the spectrum. However, this figure should be interpreted with caution due to potential discrepancies in diagnostic practices and population demographics.

The encompassing term "autism spectrum disorder" (ASD) encompasses a range of social interaction difficulties, repetitive behaviors, speech challenges, and nonverbal communication deficits (Matson & Kozlowski, 2011). This diagnosis can exert a significant negative influence on various life domains for individuals with ASD, as well as their families and communities. In essence, caring for children on the spectrum presents substantial challenges that can disrupt

family dynamics. Research has identified concerning ramifications, including heightened stress levels, diminished self-care practices, and a consequent decline in mothers' overall quality of life (Gentles et al., 2020).

Mothers and caregivers of children with ASD face a demanding landscape. Providing for these children's needs often requires a significant investment of time, effort, and patience (Bromley et al., 2004). This dedication can come at a cost, with mothers experiencing increased vulnerability to psychological distress, depression, anxiety, and a cascade of other mental and physical health issues (Bromley et al., 2004). The financial burden is another significant stressor, as out-of-pocket healthcare expenses, underemployment, or job loss are often realities for these families (Bromley et al., 2004). Unsurprisingly, the strain of caregiving frequently results in diminished quality of life for mothers of children with ASD (Khanna et al., 2011).

The World Health Organization (WHO) defines quality of life (QoL) as an individual's subjective perception of their life situation within the context of their culture, values, and personal goals. This concept encompasses various dimensions, including social, physical, psychological, spiritual, cognitive, and environmental (Kelley-Gillespie, 2009). Each of these domains can be demonstrably impacted by the caregiver burden experienced by mothers raising children with ASD. For instance, the chronic nature of ASD necessitates ongoing care, potentially leading to a significant financial strain due to both direct healthcare costs and indirect costs associated with employment limitations (Mosadeghrad & Pourreza, 2019).

Mothers of children with ASD face a multitude of challenges that significantly impact their quality of life. Employment difficulties are a frequent consequence, with many forced to leave their jobs to provide full-time care (Scott, 2018). This decision often exacerbates the financial burden associated with ASD care. Beyond financial strain, mothers experience a decline in quality of life across various domains, including social isolation, psychological distress, and physical health problems, ultimately leading to diminished happiness (Renford NG, 2020). Research consistently demonstrates elevated stress levels in mothers of children with ASD compared to mothers of typically developing children or those with other developmental disorders (McStay et al., 2014). The specific challenges documented include sleep disturbances, physical ailments, limited social interaction, marital conflict, financial strain, neglect of self-care, and chronic stress (Kuhlthau et al., 2005).

In other words, having a child with ASD generally changes the normal routine life of mothers and other family members. These changes can be positive or negative. A diagnosis of ASD in a child often disrupts pre-existing family routines and dynamics. While these changes can be positive or negative, the child with ASD frequently becomes the focal point of family life and activities, potentially leading to the neglect of other family members' needs (Mirzaie et al., 2018).

Developing evidence-based interventions for ASD in Indonesia presents a significant challenge due to the dearth of research on the specific needs and obstacles faced by ASD

specialists. Further investigation into ASD, particularly regarding assessment practices within Indonesia, is urgently required. This information is crucial for policymakers to refine assessment procedures and enhance services for individuals with ASD in Indonesia.

## RESEARCH METHODS

### Research Design

This research Employing a qualitative research design and content analysis methodology, this study explored the factors influencing the quality of life for mothers raising children with ASD in Bandung, West Java, Indonesia.

### Participant

A convenience sampling approach was utilized to recruit participants for this study. The sample included three mothers residing in Bandung, Indonesia, each with a child diagnosed with ASD. Diagnoses were confirmed by qualified physicians or psychologists according to the Diagnostic and Statistical Manual of Mental Disorders (DSM), with documented proof provided through official diagnosis letters. Additionally, all participants signed informed consent forms signifying their agreement to participate in the study. Mothers were eligible if they had at least one child with ASD and expressed willingness to participate.

The demanding and multifaceted nature of caregiving for children with ASD necessitates a nuanced understanding of the impact on mothers' lives. ASD's chronic course and potential negative prognosis can lead to a wide range of consequences for caregivers. Furthermore, the quality of

life, well-being, and health of mothers demonstrably influence the quality of care and well-being of individuals with ASD. Therefore, identifying factors affecting mothers' quality of life is crucial to inform efficient and effective interventions. This qualitative study explored parental perspectives on the factors influencing the quality of life for mothers raising children with ASD in Bandung, West Java, Indonesia.

### Data Collection Strategy

Data collection employed semi-structured interviews designed to align with the World Health Organization's (WHO) quality of life theory. The interview guide was adapted from the WHOQOL-BREF, a quantitative quality of life assessment tool. Interview durations ranged from 30 to 60 minutes, depending on individual participant response times. All interviews were conducted one-on-one via Zoom meetings.

Semi-structured interviews commenced with an initial rapport-building phase. Participants were then asked demographic questions regarding their age, their child's age and age of diagnosis, and so forth. An interview guide ensured coverage of core topics while allowing for exploration of emergent themes. In essence, the guide served as a framework for open-ended and interpretive questions, with the participant's responses shaping the interview trajectory (as shown in Table 1). Exploratory questions were strategically employed throughout to delve deeper into responses and enhance understanding. Non-verbal cues such as emotional expressions (upset, nervousness, crying) were also documented.

**Table 1. Semi-structured Interview Guide**

Questions for mothers	Objective
1. Please tell me about your child (autistic child): <ul style="list-style-type: none"> <li>• How old is she/he?</li> <li>• Could you please explain the severity of the disorder in your autistic child? (e.g: how is he/she functioning in school, home)</li> <li>• The age at which he/ she was diagnosed with ASD? What triggers it first?</li> <li>• Do you have another child?</li> </ul>	To know: <ul style="list-style-type: none"> <li>• Child conditions and its severity</li> <li>• Child's medical conditions background</li> </ul>
2. Please tell me how you perceive your life: <ul style="list-style-type: none"> <li>• How does having a child with ASD affect your life?</li> <li>• What challenges do you face as a parent of an autistic child?</li> <li>• What is your biggest worry about the future for you and your child regarding his/her condition as an autistic child? (psychological well-being)</li> <li>• How is your economic condition? Is there</li> <li>• By having an autistic child, does it affect your happiness and gratefulness?</li> <li>• Tell me about your social relationship after having an autistic child?</li> <li>• What kind of factors do you think that could help you to increase your quality of life? And what factors can reduce it?</li> </ul>	To know: <ul style="list-style-type: none"> <li>• How mothers view their own-self and its relationship with their conditions as a parent of an autistic child</li> <li>• Their view of their quality of life aspects (physical health, psychological well-being, social relation, and environment)</li> </ul>

### Data Analysis

Employing a contractual content analysis approach based on the method of Graneheim and Lundman (2004), this study analyzed the qualitative interview data. Contractual content analysis offers a systematic and objective means to describe and categorize verbal data (Graneheim & Lundman,

2004), ultimately aiming to derive valid conclusions about a specific phenomenon (Downe-Wamboldt, 1992). It surpasses simply extracting objective forms; this method allows researchers to identify and explore deeper thematic structures within the data. The analysis followed a four-step process: (1) decontextualization (identifying meaning units),

(2) recontextualization (categorizing meaningful content and excluding irrelevant content), (3) categorization (identifying homogeneous response groups), and (4) compilation (drawing well-supported conclusions). To ensure data accuracy and reliability, Guba, and Lincoln's (1989) four criteria of trustworthiness—credibility, dependability, confirmability, and transferability – were employed. In this study, establishing a long-term rapport with participants facilitated participant review, enhancing the credibility of the data and the generated codes.

### RESEARCH RESULTS

This study included three parents. Two participants reported their child receiving an autism diagnosis by age seven, while the remaining child received a diagnosis by age three. Notably, early diagnosis around age three is considered optimal for initiating early intervention programs (as shown in Table 2).

**Table 2. Participant Demographics**

Participants demographics	n=3
Age of the parents (years)	53 ± 14
Gender of the parents, n	
Male	0
Female	3
Job, n	
Working mother	1
Full housewife	2
The age of the affected child (years)	24 ± 10
The diagnosis age (years)	7 & 3
Having another child, n	
No	1
Yes	2

Analysis of the interview data revealed five core themes shaping the mothers' perspectives on their quality of life: challenges, anxieties about the future, changes in social interactions, happiness and gratitude, and factors influencing quality of life. These themes are further delineated into eleven subthemes, detailed in Table 3 for a more nuanced understanding.

**Table 3. Factors affecting the quality-of-life mothers of children with autism spectrum disorder based on theme and subtheme.**

Theme	Subtheme
Challenges	<ul style="list-style-type: none"> <li>• (S1) Fear of social judgment</li> <li>• (S2) Seeing children of the same age doing normal activities</li> </ul>
Fears about the future	<ul style="list-style-type: none"> <li>• (S3) Frightened about death and the idea of leaving the child.</li> <li>• (S4) Child's independency &amp; future working environment</li> </ul>
Changes in social interactions	<ul style="list-style-type: none"> <li>• (S5) Tendency to withdraw from public invitations.</li> <li>• (S6) Intentionally choose to interact only with the closest one.</li> </ul>

Happiness & Gratitude	<ul style="list-style-type: none"> <li>• (S7) Opportunity to gain new support system</li> <li>• (S8) Believing that happiness will come soon.</li> <li>• (S9) Willingness to live, continue life and being a humble person</li> </ul>
Factors to improve QOL	<ul style="list-style-type: none"> <li>• (S10) Spiritual &amp; religiosity</li> <li>• (S11) Pride in one's achievements dealing with the child</li> </ul>

**Challenges.** The first core theme, "Challenges," encompasses two subthemes. The first subtheme, "Fears of Social Judgment (S1)," captures mothers' anxieties about societal disapproval or discrimination. The second subtheme, "Seeing Children of the Same Age Doing Normal Activities (S2)," highlights the emotional strain associated with observing typically developing peers. Participant quotes pertaining to these challenges are presented below:

P1: "The biggest challenge is when we take our child outside home and he's behavior not behaving, I feel like I want to say sorry 'my child is autistic'. It's so overwhelming and the challenge is to deal with people's gaze and what's in their head" (S1)

P2: "The challenge is to adapt to our own expectations and their correlations with reality. For example, when seeing a kid the same age as mine dating" (S2)

**Fears about the future.** The second core theme, "Fears About the Future," is comprised of two subthemes. "Frightened About Death and the Idea of Leaving the Child (S3)" captures mothers' anxieties about their own mortality and the well-being of their child in their absence. The subtheme "Child's Independency and Future Working Environment (S4)" highlights concerns regarding their child's ability to live independently and secure employment. Participant views related to these future fears are presented below:

P3: "Ever thought. What will happen to him when we're dead." (S3)

P1: "Can he take care of himself? What if he works and has to take care of himself?" (S4)

**Changes in social interactions.** The third core theme, "Changes in Social Interactions," encompasses three subthemes. "Tendency to Withdraw from Public Invitations (S5)" highlights mothers' inclination to avoid social gatherings. "Intentionally Choose to Interact Only with the Closest One (S6)" emphasizes the preference for limited social circles. The subtheme "Opportunity to Gain New Support System (S7)" acknowledges the potential for developing new support networks. Participant experiences related to these social interaction changes are presented below:

P3: *"It is also took us for more likely to choose and do more considerations to attend family or public events"* (S5)

P3: *"Intentionally choose to be friends with those who are already act as a closest one to us."* (S6)

P2: *"Gain lots of new friends and community. Very happy. Felt like I have lots of brothers and sisters"* (S7)

**Happiness & Gratitude.** The fourth core theme, "Happiness & Gratitude," is comprised of two subthemes. "Believing that Happiness Will Come in the Near Future (S8)" captures mothers' expressions of hope and optimism for future improvements. "Willingness to Live & Continue Living and Being a Humble Person (S9)" emphasizes their resilience, perseverance, and acceptance of their situation. Participant perspectives related to these positive outlooks are presented below:

P1: *"I believe that soon there will be happiness happen to me. Peace can be created within our hearts"* (S8)

P2: *"He reminds us to always stay humble and always willing to learn"* (S9)

**Factors to improve QOL.** The fifth core theme, "Factors to Improve QOL," encompasses two subthemes. "Spiritual & Religiosity (S10)" highlights the role that faith and religious practices play in enhancing mothers' quality of life. The subtheme "Pride in One's Achievements Dealing with the Child (S11)" emphasizes the sense of accomplishment and satisfaction mothers derive from effectively caring for their child. Participant experiences related to these quality-of-life factors are presented below:

P1: *"We must have strong faith that we believe this is only temporary, that later there will be great rewards and happiness for us."* (S10)

P2: *"Feeling quite proud of myself and the efforts that have been made to help my child"* (S11)

## DISCUSSION

This qualitative study explored factors influencing the quality of life for mothers raising children with ASD in Bandung, West Java, Indonesia. Semi-structured interviews were conducted with three mothers. Thematic analysis revealed five core themes impacting the mothers' quality of life: challenges, anxieties about the future, changes in social interactions, happiness and gratitude, and factors fostering QOL. These themes are further delineated into eleven subthemes, providing a nuanced understanding of the mothers' experiences.

The World Health Organization (WHO) defines quality of life (QoL) as an individual's subjective perception of their life situation within the context of their culture, values, and personal goals (Kamali et al., 2013). This multifaceted concept serves as a valuable framework for assessing living

conditions, evaluating interventions, and informing decision-making. Research consistently demonstrates that the presence of a child with special needs, particularly ASD, significantly impacts family functioning and the well-being of mothers, often leading to a decline in their QoL (Amiri et al., 2014). A compromised QoL for primary caregivers can, in turn, negatively affect the quality of care provided to the child. Therefore, identifying factors influencing the QoL of mothers raising children with ASD is crucial for planning and implementing effective interventions. This study aimed to explore such factors impacting mothers' QoL.

Similar to findings from Ludlow et al. (2012), mothers in this study reported experiencing a fear of social judgment while raising a child with ASD. Ludlow's qualitative research described mothers confronting negative judgments from others, with stares leading to feelings of embarrassment and guilt (Ludlow et al., 2012). These findings highlight the potential social stigma associated with parenting a child with ASD, a challenge echoed by mothers in the current study.

Compounding these anxieties, mothers also expressed concerns about their child's future independence and their own mortality. This resonates with Chen (2019) who found that mothers experience heightened anxieties due to a lack of guidance in preparing their children for adulthood. It also highlights the importance of resources and support systems to navigate complex service options and fragmented information. Without such resources, mothers struggle to form realistic and positive expectations for the future (Chen et al., 2019).

Mothers in this study described feeling excluded from the world their child with ASD inhabits, aligning with Woodgate et al.'s (2008) findings of altered social interactions. This sense of exclusion may contribute to the tendency to withdraw from social gatherings observed in the present study. While mothers reported gaining support and strength from some family and friends, they also expressed feelings of isolation from extended family members who lacked understanding or failed to provide practical assistance (Woodgate et al., 2008).

According to parent's happiness and gratitude feelings, this study reported that by taking part as a parent of autistic child, they believe in a brighter future, willingness to live & continue living and being a humble person. According to the result from previous study, for many mothers they found it important to ensure that their children's differences were embraced, particularly regarding specific strengths linked to their autism. Mothers tend to focus on the positive side, for example thinking about the child's ability for being brilliant and thinking outside the box.

Beyond exploring mothers' quality of life (QoL), this study also identified potential facilitators to raise the QoL for mothers raising children with ASD. This information can serve as a valuable resource for future research endeavors. The study found that factors such as spiritual practices, a sense of accomplishment in caring for their child, and a strong motivation to support their child's development may contribute to mothers' quality of life (Crane et al., 2019).



This study's strength lies in its focus on understanding, from the mothers' perspective, the factors influencing their quality of life while raising a child with ASD. However, limitations are inherent to all research endeavors. Firstly, challenges in participant recruitment limited the ability to impose specific criteria on the children (e.g., age, gender, ASD severity). This limitation restricts the generalizability of the findings to specific populations, which could be an interesting avenue for future research. Secondly, difficulties in engaging fathers and mothers of autistic girls were encountered. This may be due to the potential gender-related differences in ASD presentation and severity.

Considering these limitations, future research is recommended to explore the quality of life of mothers raising children with ASD under more specific conditions, including investigations into fathers' perspectives and the experiences of mothers of autistic girls. This would contribute to a more comprehensive understanding of the impact of ASD on family dynamics and well-being.

### CONCLUSION

This study's findings highlight the multifaceted nature of factors impacting the quality of life (QoL) for mothers raising children with ASD. These factors encompass individual experiences, interpersonal relationships, and broader social contexts. Consequently, this research underscores the urgent need for a multi-level approach involving collaboration among various stakeholders: society, researchers, mothers themselves, schools, and government entities. The design of effective support programs should be informed by data on mothers' QoL. The World Health Organization's (WHO) strategies for improving support for individuals with ASD offer a valuable framework. These strategies emphasize empowerment alongside the importance of supportive policies, environments, and the adaptation of existing systems.

However, in Indonesia, a collectivist society, disability can be viewed as a punishment, leading to social stigma and rejection. This, in turn, can exacerbate mothers' isolation and burden. Therefore, interventions should go beyond mere societal education through community engagement. A culturally sensitive approach that acknowledges and empowers mothers' existing coping mechanisms and positive perspectives is crucial for enhancing their QoL. Ultimately, achieving positive outcomes requires coordinated efforts and collaboration among all stakeholders.

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