

# The Quality of Life of Mothers Who Have Children with Autism Spectrum Disorder

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**Abstract** Autism Spectrum Disorder (ASD) is a complex intellectual and developmental disability clinically diagnosed when s/he is 2 or three years old. These children demand special care to meet their special needs to enable optimized potentials in their development. This qualitative study aims at understanding the stressors affecting the quality of life of the primary care-giver. Parenting for children with ASD is usually more complicated and demanding than for children without disabilities. Four case studies were selected to represent typical mothers of ASD children in different phases of development. Their ages ranged from 29-50 years old and the ages of their children were 6 to 22 years old. Research credibility is constructed through interviews with significant others and observation of social media activities. The instrument for the study is WHO-QoL-BREF which is adjusted for an interview protocol. The results indicated that mothers who were not supported by their spouse and family members often had to deal with the uncertain future alone. Those who felt accomplished in caring for their children were strengthened by the parenting experiences. Support from professionals is crucial for mothers in addition to support from significant others and peers, in maintaining their quality of life.

**Keywords:** Autism Spectrum Disorder, parenting, quality of life, stigma

## 1. Background

Autism Spectrum Disorder (ASD) is a very complex developmental disorder in children, with alleged varied causes such as genetic factors, nutrient intake, electromagnetic current from household utensils and ICT, and problems in childbirth. ASD has clinical symptoms that usually recognizable in the first three years of the child's life (Peeters, 1997; NIH, 2018). Children diagnosed with ASD disorders are characterized by damage in three areas in varying degrees, namely communication skills, social interaction, and repetitive behavior (Nolen-Hoeksema, 2011). Based on The National Research Council in the United States (Wike, 2015), ASD can be found in all children in the world with various racial and ethnic backgrounds, including in Indonesia.

As children with disabilities, they need special support and treatment so that they can

develop and meet their needs (Vani, Raharjo, Hidayat, and Humaedi, 2014).

Sumantri (2007) suggests that the strongest support needed by children with disabilities comes from the family. Families, especially parents, have a crucial role in meeting the needs of children with disabilities because they are the closest proximity to the child, where a child should, under any circumstances, be entitled to have full love, attention, and assistance (Vani, Raharjo, Hidayat, & Humaedi, 2014; Nordahl-Hansen, 2018).

Parents who have children with disabilities certainly have their own burden in caring for their offspring, including parents who have children with ASD. Parents who have children with ASD need to understand the special needs of their children. They need to know how to deal with common and specific problems experienced by children with ASD (Wike, 2015; Misquitta, Brito, Ferreira, & Junior, 2015). Parents who have children with ASD also need more financial support to care for their children. They need the help of professionals, such as therapists and

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psychologists, to carry out developmental or therapeutic examinations of their children and to educate (coach) the caregivers (Leung & Li-Tsang, 2003).

Besides having a special burden in caring for their children, parents who have children with disabilities also experience pressures from stigma and discrimination in the family and larger environment. Among other members of the family, mother is usually the one to bear the burden of the disease (Riany, Cuskelly, & Meredith, 2016). In Indonesia there is a general belief that children are entrusted by God Almighty and, therefore, should be accepted with gratitude and happiness. Otherwise, the family will go through a period of loss and grieving (Waltz, 2015).

Fear and shame fueled by negative stigma and lack of understanding have serious consequences for the family and the child with disability (Gray, 2002; Waltz, 2015). Distressed parents may neglect their children and, so that it can cause parents to tend to neglect their children and fail to access services (Riany, Cuskelly, & Meredith, 2016). Some children may be abused by parents (Aryault, 2011). On the positive side, however, most parents, especially mothers, are able to bounce back from feeling of loss and grieving and try their best to help optimize their child development (Mak & Kwok, 2010).

Adversities in rearing children with ASD usually lead parents to experience roller-coaster emotional and mental conditions which affect their quality life (Misquitte, Brito, Ferreira, & Junior, 2015). Many parents (mother) experience heightened anxiety due to unexpected daily events related to their child condition, for example when a child with ASD experiences sudden tantrums (Abbeduto, Seltzer, Shattuc, Krauss, Orsmond, & Murphy, 2004). Generally, children who have ASD disorders have difficulty in making friends and understanding social rules. It is also common that ASD children only have one particular interest that they do repeatedly (Ernsberger, 2006). Difficulties in making friends and understanding social rules experienced by ASD children can also cause parents to feel overly anxious, especially when their children have entered school age.

## 2. Quality of Life According to WHO

Quality of life is a construct that measures a person's overall well-being and status, which is influenced by one's physical health and mental well-being (Lee, Lopata, Volker, Thomeer, Nida, Toomey, & Sabrina, & Chow, 2014).

The World Health Organization (WHO) explains that quality of life is an individual's perception of their position in life, in the context of values and culture in their environment, which is related to their goals, expectations, standards, and life focus.

Quality of life is an abstract concept that is influenced in a complex way by one's physical health, psychological condition, beliefs, social relationships, and environment. (World Health Organization, 2002). WHO has created a measuring tool to measure quality of life for a survey named WHOQoL and the shortened version is called WHOQoL-BREF. This instrument measures the quality of a person's life based on four domains, namely physical, psychological, social relations, and the environment.

Quality of life as a measure of the burden experienced by mothers who have children with ASD will be constructed from their answers to the WHO-QoL-BREF interview schedule which will be induced as themes and subthemes for analysis

It is well-established that childcare is not an individual task of parents, but a systemic task in the family system. In many communities, however, mother is the party that most often invests time, energy, alertness, and persistence in parenting compared to other members of the family (Misquitte, Brito, Ferreira, & Junior, 2015). She has to accommodate sources of stress coming from the new routine, unexpected events, and harmful situations related to the child behavior (Abbeduto, et al., 2004). Therefore, it is understood that a mother who has a child with ASD also experiences high physical and psychological demands in caring for their child (White & Hastings, 2004).

## 3. Purpose of study

This research aims to understand the psychological burden or stressor of mothers or

primary caregivers of children with Autism Spectrum Disorder (ASD) and what impact these burdens have on their quality of life. To achieve the purpose, this study asks the following research question: *What are the psychological stressors experienced by mothers of children with ASD that are related to WHO-QoL-BREF quality indicators?*

## 4. Research method

This is an exploratory study using a qualitative method to get more in-depth understanding of the complexity of mothers' parenting children with ASD and how parenting adversities affect their psychological well-being. In addition, children with disabilities, including ASD, is a very sensitive issue to discuss with caregivers. Therefore, without a good rapport it will be very difficult to get participants (Poerwandari, 1998).

Data and information about stressors are obtained using open interviews about Mother's daily activities and various challenges faced in raising children. Data and information on Quality of Life is obtained by turning WHO-QoL-BREF into an open interview instrument with probing questions.

Inclusion criteria for participants are mothers who have children with ASD and play an active role in caring for their children. In addition, participants in this study are also mothers who live in Jakarta and surrounding areas. Another criterion is that the researchers are given permission to become friends and connect with their social media (Facebook) for the sake of research credibility.

Maximal Variation Sampling technique was used in finding participants in this study to obtain a number of participants (Creswell, 2012) who have different demographic characteristics of both mothers and children and the availability of support from partners or husbands. During the selection process, the researcher tried to introduce herself through social media (Facebook) and requests to meet for an interview. The researcher chose mothers who have children with different age categories. In addition to the age of the child, researchers also chose participants who had different educational backgrounds, marital status, beliefs, and location of residence.

Recruitment was confirmed after the introduction through Facebook and promised to meet. The researcher explains the purpose of the research and asked the willingness of mothers to participate in this study. Agreements were made in writing (signature of consent).

## 5. Results and Discussion

### 5.1. Overview of Physical Health Quality

Based on in-depth interviews, Dian, Ibu Emma and Ana (not names) said that their physical condition was not affected by the burden of caring for their children who were diagnosed with ASD. The same three participants also said that they did not have sleep problems. Only Ms. Novi said that her physical condition and quality of sleep were affected by the condition of her child who was diagnosed with ASD. The results also showed that the four participants did not have a dependency on drugs. Ms. Ana said that she took vitamins to maintain health at an advanced age, and Ms. Novi said that she always tried to recover as quickly as possible when she was sick.

### 5.2. Overview of the Quality of Psychological Health

During the in-depth interview, three Mothers stated that they did not feel ashamed of their children's condition. Those times have passed. Ms. Novi, Ms. Dian, Ms. Emma, and Ms. Ana. Ms. Ana can always tell the people around them about the condition of their child who was diagnosed with ASD. Ms. Dian said that she was already used to negative views from people regarding her child's condition. Ms. Ana always tries to educate people, especially her immediate environment, regarding her child's condition. Ms. Ana also said that she did not care about the negative views of other people. According to her, the most important thing is that people already know the true condition of her child.

Researcher's observation, however, suggests different findings. Two participants, namely Ms. Novi and Ms. Ana, showed some indications that they were still trying to overcome the negative views of other people. Ms. Novi said that she was still often annoyed at the negative views that were directed to her child. The feeling of annoyance felt by Ms.

Novi disturbed her mind and affects the quality of her sleep. As for Emma, she said that she still felt ashamed when her child did something inappropriate in public. Ms. Emma's statements when interviewed also showed that she is still trying to overcome the shame associated with her child's condition.

### **V.3. Overview of the Quality of Social Health**

The results of the interview show that each participant has a different picture of social relations. When collecting data, the researcher asks participants whether they share the diagnosis of their children with members of their larger families. Ms. Novi and Ms. Dian said that they were not the type of people to share the burden they were experiencing even with those closest to them.

Ms. Novi and Ms. Dian said that they still get negative views from other family members regarding their children's condition. When that happens, they rely on themselves to deal with the pressures. They do fun activities for themselves. Ms. Emma said that she always prayed when she was experiencing a lot of pressure, but she still had her youngest child as a friend to tell. Ms. Ana is a participant who has a lot of support systems.

### **V.4 Overview of Quality of Relationship with the Environment**

The four participants said that the costs required to consult with professionals, therapists, or to pay for education of children diagnosed with ASD were indeed quite high. Two participants in this study, Ms. Novi and Ms. Emma, did not say that they had difficulty meeting their children's financial needs. One participant, Ms. Dian, said that she had experienced financial difficulties to meet her children's therapy and education needs, because at that time she was experiencing problems in her career. At that time, Ms. Dian received help from her parents.

Different from the other three participants, Ms. Ana often gets sufficient support and opportunities to access good education and specific therapy needed for her child. Ms. Ana has her own creative ways to access seminars or workshops that she thinks appropriate for the development of her ASD child.

One of the limitations of this study is the partial knowledge about the burden of parenting children with ASD which is obtained only by the quality of life of mothers. Since parenting is a systemic affair, acquiring knowledge about the burden of parents (father and mother) presents its own methodological challenges. If various burdens can already be mapped for both parents, future research methodologies can be more creative in seeking convergence or similarities and differences between the two parental actors.

The next limitation is social desirability because of the sensitivity of the topic. A lot of responses of the participants were normative and superficial and needed probing. When rapport and trust were established, it was easier to get more honest answers. Otherwise, participants were irritated and refused to engage in further interview. It is, therefore, very important that the researcher have access to close relatives and their respective social media for triangulation. In addition, social media remains the primary data source because it comes from the participants themselves. Through triangulation conducted through sources on social media, they provide additional information that is not told to the researcher but told to their friends, such as experiences of stigma, or bullying experienced by their children.

Very short observations, although accompanied by social media triangulation, still do not allow researchers to obtain in-depth information about the socio-psychological impact of mothers who include their ASD children. Therefore, the reader is expected to be careful not to make broader generalizations outside the experience of the mothers of the study participants.

This research was also greatly helped by the emergence of literature on ASD from the perspective of caregivers so researchers can build various assumptions that can be used as indicator variables in this study (Misquitte, Brito, Ferreira, & Junior, 2015; Nordahl-Hansen, 2018; Waltz, 2015).

## **5. Conclusion**

This study shows that the care of children with ASD imposes varying mental and physical burdens on their mothers. Although mothers tend not to take the burden very seriously, it is

recognized that there is an impact on their health and sleep quality.

Mothers who have children with ASD quite often feel anxiety related to their children. The anxiety they feel is usually related to the limitations that children have, their particular needs and behavior, and the views or treatment of people around them who are not yet familiar with their child's condition. In addition, feelings of anxiety are also felt related to their capacity to access the facilities provided, such as schools, therapy centers, and others.

Although they have tried to overcome feelings of anger and shame related to their children's disabilities, there are still mothers struggling to overcome these feelings. Of course, this is dependent on the severity and age of children with disabilities and the support of close family members. Even though they have tried to be open about their child's condition, not everyone can provide support. Children with ASD still get negative views from people around them, especially from people who don't know what autism is. Negative views given by people can affect the quality of a mother's psychological health, even though they try to ignore that negative view.

Although the costs required by parents for their child to be diagnosed with ASD are high, all parents interviewed were able to mobilize the resources they have. This does not mean that mothers who have children with ASD are not burdened financially, even though there may not be found in the interview who complained about this.

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Tabel 1  
Quality of Life According to the World Health Organization

Domain	Indicator
Physical Health	Daily activities
	Dependence on drugs or medical treatment
	Energy and fatigue
	Mobility
	Pain and discomfort
	Sleep and rest
	Working Capacity
Psychological	Body view and appearance
	Negative feelings
	Positive feelings
	Confidence
	Spirituality / religion / belief
	Thinking, learning, memory and concentration
Social Relationship	Personal relationship
	Social support
	Sexual activity
Environment	Financial sources
	Feeling of freedom, security and physical safety
	Health and social facilities: accessibility and quality
	Home environment
	Opportunities to acquire new information and expertise
	Opportunities for recreation or leisure time
	Physical environment (pollution / noise / traffic / climate)

Tabel 2  
Participants of This Research

Name	Ms.Novi	Ms. Dian	Ms. Emma	Ms. Ana
Age	29	49	50	56
Martital	Married	Discover	Discover	Married
Status				
Residential Area	North Jakarta	South/East Jakarta	Tangerang	East Jakarta
Religion	Catholic	Islam	Christian	Islam
Occupation	Housewife	Project Manager/Nutrition Doctor	Housewife	Child with Special Needs Therapist
Educational Background	SMK - Tourism	Doctorate of Medicine – Nutrition Specialist	Undergraduate of Economics	Undergraduate of Business Administration

<b>Ethnicity</b>	Chinese – East Java	Central Java	Chinese – Central Java	Central Java
<b>Age of Child with ASD</b>	6	12	18	22
<b>The Order of Child's Birth</b>	First child from two	Second child from two	First child from two	Second child from two
<b>Gender</b>	Male	Male	Female	Male

Tabel 3  
Overview of the Quality of Psychological Health

<b>Ms. Novi</b>	<b>Ms. Dian</b>	<b>Ms. Emma</b>	<b>Ms. Ana</b>
Often experiences anxiety about her child. She also feels resentful about stigma surrounding her child, which sometimes makes it difficult to sleep.	Not really expressing her negative feelings or stigma about her child. Ms. Dian prefers not to bother with it all.	Often feels anxious about what her child will do, especially when dealing with other people. She also feels sad when her son received stigma and was rejected by his friends.	Not bothered by people who judge her child negatively, because she feels that she has a very supportive environment, especially her family.
She is not ashamed to tell others that her child has been diagnosed with Autism.	She is not ashamed to tell others that her child has been diagnosed with Autism. At first she was annoyed with the negative judgments given by others, but now she feels used to it and chooses not to care about it	She is not ashamed to tell others that her child has been diagnosed with Autism, but she has felt embarrassed and worried when her child does things that make other people uncomfortable in public.	She is not ashamed to tell others that her child has been diagnosed with Autism. She prefers to open up to others and educate them. Ms. Ana doesn't care if other people give negative judgments
Does not mind taking her children to travel and meet new people, her concern is she's afraid that her child will do things that make other people uncomfortable	She said that she rather not to come if she was invited by her friends to travel with her child because she felt it would be troublesome later.	She doesn't mind taking her children to travel and meet new people. For her, this is another way to educate her children about meeting new people, even though sometimes she was	She doesn't mind taking her children to travel and meet new people. For her, this is another way to educate her children about meeting new people.



		embarrassed by her child's actions.	
Feels confident that her child can successfully develop like other children.	Feels happy when her child does something beyond her expectations.	Feels happy to see the progress of her child who has gotten better.	She feels good to see her child and other children whom she is treating have developed better. She also feels grateful to have a very supportive family and environment for her child.

Tabel 4  
Overview of the Quality of Social Health

Ms. Novi	Ms. Dian	Ms. Emma	Ms. Ana
Mostly relies on herself when she's under a lot of pressure about her child.	Mostly relies on herself when she's under a lot of pressure about her child.	She feels like she can rely on her second child when she's under a lot pressure. She also prays everytime she feels burdened.	She has a lot of support, from her family, her husband, her first child, and her friends. She can rely on them whenever she feels burdened.
Still get negative judgements from her extended families, and have not received full support from her husband.	Still get negative judgements from her extended families.	She feels like finally she strated receiving support from her extended family.	She gets all the support from all family members, both the nuclear family and extended family.

Tabel 5  
 Overview of the Quality of Relationship with the Environment

<b>Ms. Novi</b>	<b>Ms. Dian</b>	<b>Ms. Emma</b>	<b>Ms. Ana</b>
The financial source comes from the husband.	The financial source comes from herself.	The financial source comes from herself.	The financial source comes from herself and her husband.
Feeling that the needs of ASD children cost higher than normal children, but did not express financial difficulties.	She said back then. she was in trouble financially, especially when her husband died, but she got help from her parents.	She said never had financial difficulties.	Feeling that the needs of ASD children cost higher, but did not express financial difficulties.