

# Assessing Caregiver Burden and its Correlation to Quality of Life of Mother with Autism Spectrum Disorder in Surabaya Indonesia

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## Abstract

Autism Spectrum Disorder (ASD) is a complex neurological disorder that affects brain function and occurs within the first three years of life and cause disorder in several areas of development including social interaction, communication and behavior. Mother, as primary caregiver is the most affected subject during nurturing. Mother's quality of life is very important for mother's wellbeing. The aim of this study is to determine the relationship between caregiver burden with quality of life of mothers with autistic child. This study is an analytic cross sectional design using consecutive sampling in psychiatric day care Dr. Soetomo General Hospital, Surabaya. Instrument using Caregiver Burden Assessment (CBA) and WHO QoL BREF to assess mother's quality of life. The sample for this study consisted of 24 mothers of children with autism spectrum disorders. Objective burden showed a significant negative correlation with physical, psychological, and social domains quality of life and did not correlate to environmental domain of quality of life. Subjective burden and total caregiver burden did not correlate to all domain of quality of life of mother with autism spectrum disorders children.

## Keywords

Caregiver Burden, Quality of life, Mother of Children with Autism Spectrum Disorder

## 1. Introduction

Autism Spectrum Disorder (ASD) is a complex neurological disorder that affects brain function and usually occurs within the first three years of life. ASD cause disruption in some areas of development including social interaction, communication, and behaviour. The Center for Disease Control (2012) reported 1 in 88 children diagnosed with ASD (Bashir et al., 2014). In 2013, it is estimated more than 112,000 children with autism spectrum disorder in the age of 5-19 years in Indonesia (Judarwanto, 2015). Children with ASD show some symptoms that can be stressful for the families. Various changes are also experienced by families who daily facing and caring for children with ASD. In fact, the family also had to sacrifice for the development and growth of their child with ASD (Apostelina, 2012).

Some parents quit their jobs and could not enjoy daily activities because they have to take care for their children with ASD that require special treatment than other children. According to previous research by Anjari in 2016, parents who have children with ASD experience various problems due to lack of knowledge about autism, economic constraints experienced by parents for having to finance the child, time consumed and physical exhaustion (Misquiatti et al., 2015). In addition, parents of children with ASD also experience various emotions associated with nurturing that includes frustration, anxiety, helplessness, anger, sadness, financial problems, burden, chaos of

planned activities, and limitations in recreation. Family focus only on short-term goals compared to long-term goals (Apostelina, 2012; Bashir et al., 2014). In other studies, mothers of children with ASD experience more severe problems when compared with mothers of children with physical disability, Down's syndrome, or healthy children. This can lead to burden on family members, especially mother (Pisula, 2011).

On his study Hoefman describes the impact of caregiving on parents of children with autism spectrum disorders (ASDs). Secondly, we investigate construct validation of the care-related quality of life instrument (CarerQol) measuring impact of caregiving. Primary caregivers of children with ASDs were included. Many parents experienced considerable problems combining daily activities with care, had financial problems or suffered from depressive mood. Validity tests showed that a higher impact of caring on the CarerQol was positively associated with higher subjective burden and lower family quality of life. Most of the associations between CarerQol scores and background characteristics confirmed previous research. The CarerQol validly measures the impact of caregiving for children with ASDs on caregivers in our sample. The CarerQol may therefore be useful for including parent outcomes in research on ASDs (Hoefman et al., 2014).

In other study Kavaliotis in 2017 describe about autism is linked to bodily and psychological challenges for the parents who raise autistic children, it creates increased stress levels and reduced resilience because of these factors. However, many parents face the additional problem of the weakness to cope with the expenses of each therapeutic intervention, whereas often they are not adequately educated so as to be able to manage properly the information about the treatment of autism and maybe also its intake as a compulsory condition for the family environment. The writer explored the effect of family income and the parents' educational level on the reduction of resilience through a quantitative research based on a population sample that consisted of the parents of 312 autistic children in Greece, all of them couples, namely 624 men and women, divided in equal numbers. The important impact of the annual family income on the shaping of the levels of the characteristics under study is confirmed, as the result that was drawn is that the level of financial strength is positively connected to the social support the parents receive and the resilience they develop. Likewise, the level of education is linked to social support. The social support increases when the educational level is higher, on the contrary, the opposite goes for the levels of the total stress, parental distress, parent-child dysfunctional interaction, difficulty of child, which the lower educational level increases (Kavaliotis, 2017).

Therefore, a study to determine relationship of caregiver burden with quality of life of mothers with autism spectrum disorder child is very important to do in order to support the success of intervention in autism spectrum disorders.

## **2. Method**

### **2.1. Participants**

Participant consisted 24 mothers of children with autism spectrum disorder in Psychiatric Day Care, Dr. Soetomo General Hospital, Surabaya. This study is an analytic cross sectionals design using consecutive sampling.

### **2.2. Procedures**

A self-rated questionnaire was distributed to the subject by the author after introducing the study and obtaining their informed consent.

### **2.3. Instruments**

The study using two questionnaires. Caregiver Burden Assessment is used to assess the level of burden experienced by mothers who care for children with ASD. The CBA questionnaire was compiled by (Karimah, 2008; Putri, D; Konginan, A; Mardiana, 2014) partly adapted from Zarit Burden Scale and The Montgomery Borgotta Caregiver Burden Scale. The Caregiver Burden Assessment consists of 39 points questions that measure the subjective and objective burden. This questionnaire has been validated by Karimah in 2008. Reliability of CBA measuring instruments expressed with alpha value Cronbach 0.936 for subjective burden and 0.925 for objective burden (Karimah, 2008).

WHO Quality of life-BREF is prepared by the World Health Organization (WHO) and has been translated into Bahasa Indonesia by a representative from Indonesia, Dr. Ratna Mardiaty, Satya Joewana, Dr. Hartati Kurniadi, Isfandari and Riza Sarasvita. Validation in Indonesian has been done by (Wulandari, 2004). Reliability of WHOQOL-BREF measuring instrument using Cronbach's alpha Test produces internal consistency between 0.6138-

0,7808 (Wulandari, 2004). WHOQOL-BREF consists of 26 questions. The data are then classified into five categories: very unsatisfactory, unsatisfactory, mediocre, satisfying and very satisfying. WHOQOL-BREF assess 4 domains of quality of life, that are, physical health, psychological, social relationship, and environment (Onayli, 2010; Sanjaya, 2016).

## 2.4. Statistical analysis

The data distribution is processed using SPSS 17.0. Caregiver burden assesment that represented in objective, subjective and total score is statistical analized to quality of life that represented in 4 domains.

## 3. Results

### 3.1. Demographic

Majority participants were in the age range <28 years old (29.2%) and in the age range 28-35 years (29.2%). Most of the subjects were married 95.8% and only 4.2% were divorced (single parent). The level education of partipant in senior high school is 58.3% and did not work with percentage of 66,7%. During nurturing their children withASD, 83.3% did not receive help from other people or families and 45.8% used democratic parenting, see the table 1 below.

Table 1. Demography data

		n	%
Mother Age Categories	< 28 years	7	29,2%
	28-35 years	7	29,2%
	36-42 years	4	16,7%
	> 42 years	6	25,0%
Children Age Categories	< 4 years	7	29,2%
	4-6 years	7	29,2%
	7-9 years	6	25,0%
	> 9 years	4	16,7%
Marriage Status	Married	23	95,8%
	Single parent	1	4,2%
Education Background	Elementary School	1	4,2%
	Junior High School	3	12,5%
	Senior High School	14	58,3%
	Undergraduate	6	25,0%
Mother Occupation	No	0	0,0%
	Work at Home	5	20,8%
	No	16	66,7%
	Work Outdoors	3	12,5%
income	< 1 M	2	8,3%
	1 M - 3 M	8	33,3%
	3 M - 5 M	10	41,7%
	> 5 M	4	16,7%
Parenting	authoritarian	3	12,5%
	Demokratic	11	45,8%
	Permissive	6	25,0%
Diagnosed	combine	4	16,7%
	< 1 years	2	8,3%
	1 - 5 years	20	83,3%
Assistance	> 5 years	2	8,3%
	Yes	4	16,7%
	No	20	83,3%

### 3.2. Caregiver burden

Participants with very low objective burden level is 13%, low objective burden as much as 29%, medium objective burden as much as 50%, and high objectives burden is 8% and no participant with very high level objective burden.

Participants that had a very low subjective burden is 4%, a low subjective burden is 4%, a medium subjective burden is 46%, and a high subjective burden is 33%, and a high subjective burden is 4%. Participants who experienced very low level of burden is 4%, low level burden is 4%, medium level burden is 50%, high level burden is 34%, and very high is 8%.

### **3.3. Quality of life**

The quality of life, especially physical health domain, 66.67% participant expressed satisfaction. In psychological domain, 62.50% participants expressed satisfaction, 50% of subjects stated satisfied in social relationship domain, and in environmental domain, 62.50% of participants expressed satisfaction. However, as a note, it is still about 30-50% of participants expressed not satisfied with their quality of life.

### **3.4. Correlation between Caregiver burden and Quality of life**

From Pearson correlation test analysis, objective burden has a significant relationship with the quality of life both in the domain of physical health, psychological, and social relations ( $p < 0,05$ ). The objective burden has a negative relationship with the domain of physical health and social interaction. The objective burden also has a strong negative relationship with the psychological domain which means that the higher objective burden value, correlate to the lower psychological domain on the quality of life (Macedo et al., 2015). Objective burden shows no relation to the environment domain on quality of life. While subjective burden does not show a meaningful relationship with all domains of quality of life (Dardas and Ahmad, 2014). According to Spearman correlation test obtained the total score of caregiver burden has no relationship with all domains of quality of life.

## **4. Discussion**

Most participants experienced objective burden and subjective burden with moderate level which means that mothers with children with autism spectrum disorders experienced negative physical and mental effects due to parenting. This is in accordance with previous research in Vietnam, that caregivers experience high-level burden during parenting with autism spectrum disorders. Burden experienced by caregiver is influenced by many factors. (ANH, 2015). In this study, the objective burden can be influenced because of majority participants care for their own children without any help from others (83%). Mothers of children with ASD who care for their own children without the help of others will, of course, experience more severe emotional and physical burdens. According to Mak and Kwok, the wellbeing of parents who nurture children with GSA is strongly influenced by the support of family, friends or other health professionals (Mak and Kwok, 2010). In addition, a culture similar to Indonesia that is in Vietnam, self-blame that considers autism in children is a punishment from god for parents' mistakes, in this case mother's wellbeing will decrease and can cause burden (Mak and Kwok, 2010; ANH, 2015). In this study, the majority of mothers did not work because mothers focus on caring for their children. Excessive time to care for a child with ASD, will cause a burden for the mother (Misquiatti et al., 2015). In addition, the factor that can cause the burden is because the mother does not work. Mothers of children with ASD who did not work experience more burdens because socially the mothers become more isolated, just focus on thinking of children with ASD. The non-working mother of a child with ASD has a lower total family income when compared to both working father and mother. This is also supported by the evidence that only a small proportion have a proper income. This economic burden can also cause burden on the mother (Al-Dujaili and Al-Mossawy, 2017).

Domain of social relations on quality of life has the worst level of satisfaction when compared to other domains. This could be because caregiver mothers with ASD children have less time to socialize with the environment. 80% respondents did not work and focus on taking care of children at home which of course makes more social relationships with friends and society decreases. Children with ASD have disabilities and accompanied by symptoms of aggressiveness and hyperactivity that restrict caregiver to socialize to others (Misquiatti et al., 2015).

The most participant show satisfied in physical health domain quality of life. In this study, satisfaction with physical health occur because the majority of participants or mothers of children with ASD under the age of 35 years who certainly still have good health quality.

Objective burden has a significant relationship with the quality of life especially the psychological domain, social relationship and physical health. This relationship is negative strong correlation. This shows the higher the objective burden, the worse the domain of quality of life. This result is in accordance with the research that has been done in Uni Emirat Arab, that found the relationship between the burden with quality of life (Ezzat, Bayoumi and

Samarkandi, 2017). The psychological domain is most closely related because emotionally the mother with the ASD child is affected by it. This is in accordance with research by Almansour et al. who stated that autism is associated with stress and psychological burden for caregiver with the symptoms of depression and anxiety (Almansour et al., 2013). Caregiver burden can occur to the caregiver who treat patients with chronic illnesses including children with Autism spectrum disorder because children with ASD require special care and are highly dependent on caregivers. This has an impact on caregivers and causes high stress level to caregivers. Several theories suggest that developmental disorders in children with autism spectrum disorders have several major implications for family dynamics. These implications are physical and mental burdens arising from daily tasks, high levels of stress on family members and low levels of quality of life. Changes due to these implications occur in the daily activities and psychological functioning of family members, heavy workloads, and special demands. These changes can interfere with aspects that refer to family, work, social and personal life and can affect the emergence of conflict in caregivers. Each family member will develop adaptability and resistance to these stressors in order to maintain a good quality of life (Misquatti et al., 2015).

Symptoms in children with autism spectrum disorders are lack of social relationships and communication, and repetitive behaviour patterns that lead to caregiver stressors. However, several studies related to this theory are still controversial with different results. The most typical sign and symptom of autism spectrum disorder is a deficit in socio-emotional development. Children with autism spectrum disorders have difficulty initiating and maintaining interactions to others. Interpersonal relationship difficulties vary in severity in children with autism spectrum disorders. Study on parents of children newly diagnosed with autism spectrum disorder (ASD), explain that deficits in social interaction became a significant burden on parents. The symptom of autism spectrum disorder that causes increased parental stress is limited communication with the child. Communication deficits are seen in a variety of verbal and nonverbal skills: gestures, intonation, melody, speech rhythm, facial expressions and body language. Mothers of children with autism spectrum disorders report higher stress when their child has poor communication skills. It should also be mentioned that lack of communication is usually the main reason why parents seek professional help. Another predictor of parental stress is behaviour problems such as aggression and self-harm. Challenging behaviour of the child, apart from causing immediate problems by endangering the safety of the child or others or causing material damage, can also lead to community isolation of parents. In addition, parents often feel helpless because of child's response to their attempts to calm him down is completely unpredictable. Impaired adaptive function, including lack of daily life skills, can also increase the burden on parents. Children with low levels of self-care skills need more assistance with daily tasks which include dressing, eating, and daily hygiene from the caregiver. With the accumulation of these demands along with other behavioural problems, it is not surprising that caregiver with autistic children tend to be burdened (Pisula, 2011).

In addition, caregiver burden can occur due to psychosocial factors. The economic condition of the family has a significant effect on caregiver burden. The higher economic level of parents with children with autism spectrum disorder, the higher social support they have, the higher resilience and less severe the stress they experience. Good economic family conditions are expected to help cope with the stress of parents, because the care of children with autism spectrum disorders requires a high cost than a normal child. In addition to economic factors, the level of education of parents is also strongly related to social support received by parents of autistic children. The higher parent education level, the greater social support they have. Level of education is also related to the resilience of parents as a whole. Parents with lower levels of education have less awareness in caring for children. In addition, a study found that the emotional symptoms of autism are significantly related to parental education levels, stress experienced, as well as personality characteristics (Kavaliotis, 2017).

Another domain quality of life most closely related to objective burden is social relationship. Mothers who experience the burden of course emotionally feel often depressed and anxious, this is also causes mother isolation from social interaction. This isolation will cause burden because it also cause lack of social support. Physical health domains also have strong relationship with objective burden. The higher the objective burden will diminish physical health domain on the quality of life. This is in accordance with the theory that caregiver of children with autism spectrum disorder require greater energy to cope with symptoms when children are hyperactive, aggressive or emotionally irritable. The mother of children with ASD have to care their child with full time so mothers did not have enough time sleep and dissatisfied sleep. It caused decrease conditions in physical health.

Total caregiver burden did not show a significant relationship with the quality of life of mothers with ASD children. The subjective burden also does not indicate a significant relationship with the quality of life of the mother with a

ASD child. This is in accordance with previous research, because subjective burden is a negative perception of caregiver due to the process of caring for children with ASD.

## 5. Conclusions

Objective burden have a negative strong relationship with quality of life of mothers with ASD children in psychological, physical health and social relationships domains. A broader study with larger samples is needed to determine the overall picture of caregiver conditions of mothers with autism spectrum disorder children to create a new policy foundation for mother's wellbeing and comprehensive therapy needed to caregiver, especially mother with ASD children.

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