

ORIGINAL ARTICLE

Caregiver Burden And Psychosocial Factors In Mothers With Autism Spectrum Disorder Children

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ABSTRACT

Introduction: Burden experienced by mother can delayed the success of therapy to ASD children. This study aims to determine the correlation of psychosocial factors and caregiver burden in mothers with ASD children.

Methods: This study was a cross-sectional analytic study on mothers with ASD children at the Children's Daycare Dr. Soetomo General Hospital. The research instrument used sociodemographic questionnaire and a Caregiver Burden Assessment (CBA). Results: This study was followed by 26 mothers with ASD children.

Results: The results showed that 50% of mothers experienced moderate burdens and 34% experienced severe burdens. The results of the correlation analysis showed a significant relationship between caregiver burden and maternal age ($p < 0.05$, $r = 0.316$) and child age ($p < 0.05$, $r = 0.274$). Support and assistance from others in caring for GSA children also correlated with the mother's caregiver burden ($p < 0.05$, $r = 0.118$). Maternal caregiver burden is not correlated with marital status, education level, occupation, and economic status.

Conclusion: Mothers with ASD children experience a psychological burden while caring for ASD children. Psychosocial support and assistance from the environment are urgently needed to reduce the caregiver burden on mothers so that they can improve the outcomes of interventions and therapy for children with ASD.

Introduction

Autism Spectrum Disorder (ASD) is a complex neurological disorder that affects brain function and usually appears in the first three years of life. This causes impairment in several areas of development including social interaction, communication, and behaviour. The Centre for Disease Control (2012) reports that 1 in 88 children is diagnosed with ASD.¹ In Indonesia, cohort study in baby that birth between June 1984 and May 1991, there are 12 per 10.000 baby were diagnosed as ASD.² Children with ASD show several symptoms that can cause stress for the families who care for them. Various changes are also experienced by families who face and care for children with ASD every day. In fact, families also have to sacrifice for the development and growth of their children.³

Parents who have ASD children experience stressful situation. It is associated with reduced ability to socialize with others and therapy process for their children.⁴ Some parents quit their jobs and cannot

enjoy daily activities because they have to care for and take care of children with ASD who need special treatment compared to other children. According to the results of research by Anjari in 2016 it was found that parents who have children with ASD experience various problems due to lack of knowledge about autism, economic constraints experienced by parents because they have to pay for the child, time taken up and physical exhaustion. In addition, parents of children with ASD also experience various emotions associated with raising/caring for these children which include frustration, anxiety, restlessness, surprise, helplessness, anger, sadness, annoyance, financial strains, burdens in parenting, confusion. from planned activities, limitations in traveling, changes in plans in a short time, and family focus only on short-term goals compared to long-term goals.^{1,3} Parents with ASD children also had a high level of stress.⁵ In several other studies, it was also stated that mothers of children with ASD experienced more severe problems



when compared to mothers of children with physical disabilities, Down's syndrome, or healthy children. This can lead to the emergence of a burden on family members and mothers in particular.⁶ Caregiver burden also become one of stress factor to parents.⁷ The success of child therapy with ASD is strongly influenced by the role and support of parents as caregivers. For this reason, it is very necessary to research on psychosocial factors that affect the caregiver burden for mothers with ASD children so that the caregiver burden on mothers can be anticipated by both doctors and parents.

Methods

This research is an analytic study with a cross-sectional design of mothers of children with autism spectrum disorder at Children Day Care, Dr. Soetomo General Academic Hospital, Surabaya. The research tool used in this study is the sociodemographic questionnaire and Caregiver Burden Assessment (CBA). Caregiver Burden Assessment is used to assess the level of burden experienced by mothers who caring for children with ASD. This CBA was compiled by Karimah (2008) whose contents were partially adapted from the Zarit Burden Scale and The Montgomery Borgotta Caregiver Burden Scale. Caregiver burden assessment consists of 39 items that measure subjective and objective burdens. This questionnaire was validated by Karimah in 2008. The reliability of the CBA measuring instrument is stated by the Cronbach alpha value of 0.936 for the subjective burden and 0.925 for the objective burden.⁸ This study received ethical approval from the Ethics Committee of Dr. Soetomo General Academic Hospital, Surabaya.

Results

There are 24 research subjects who are willing to participate in this research. This number represents the total number of research subjects during a 1-month visit at the Children's Daycare Dr. Soetomo General Academic Hospital, Surabaya. the majority of research subjects were married (95.8%) and the highest education level was high school (58.3%). the majority of mothers who participate in this research were unemployed (66.7%) and had no assistance in caring children with ASD (83.3%). the majority of children with ASD were first diagnosed at the age of 1-5 years (83.3%).

Research subjects who experience moderate levels of burden are 50%, high levels are 34%, and very high are 8%, while the level of burden is very low as much as 4%, and low levels as much as 4% (see figure 1). Caregiver burden on mothers with children with autism spectrum disorders is influenced by several maternal psychosocial conditions. From the analysis test results, it was found that the caregiver burden of the mother was related to the mother's age ($p < 0.05$). In addition, the caregiver burden is also related to the child's age ($p < 0.05$) and the support and assistance from the family in parenting. The results of the correlation analysis between psychosocial factors and caregiver burden on mothers with ASD children shows on the table 1.

Table 1. Correlation analysis between psychosocial factors and caregiver burden

Psychosocial factor	Caregiver burden	
	Correlation coefficient (r)	P value
Mother's Age	0.316	0.004
Child's Age	0.274	0.014
Marital status	0.260	0.669
Mother's Education Level	0.204	0.093
Mother's Work	0.038	0.899
Salary	0.055	0.955
age of child diagnosed	0.118	0.209
Support or assistance	0.118	0.028

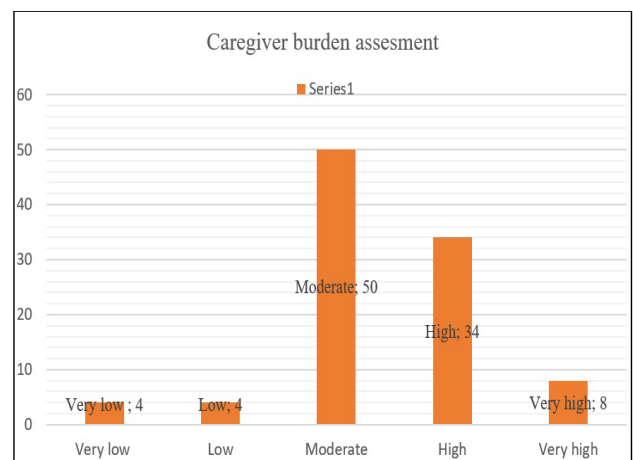


Figure 1. Caregiver burden assesment

Discussion

Most of the mothers experience a moderate to high level of burden, which means that mothers with children with autism spectrum disorders experience negative physical and mental effects due to parenting activities. This is consistent with previous research in Vietnam, that caregivers experience a high level of burden during the care of children with autism spectrum disorders. Burden experienced by caregivers is influenced by many factors.⁹ This finding also accordance with research from Nepal that stated caregiver who caring ASD children had moderate to severe burden.¹⁰ Study in Najav Province, Iraq, also stated that caregiver of ASD children experienced moderate level burden.¹¹ In a study by Lerthattasilp et al in Thailand in 2015, it was stated that 45% of caregivers of children with autism spectrum disorders experienced a mild to moderate burden and 8-10% experienced a very high burden. In addition to burden, 5.9% of caregivers also experience depression. According to the results of research by Lerthattasilp et al., the burden experienced by mothers is related to the length of time the patient was diagnosed, the symptoms of autism in children and the length of parenting.¹² According to Al Mansour and colleagues, autism is related to stress and psychological burden for caregivers with symptoms of depression and anxiety.¹³ According to Hoefman et al., children with autism spectrum disorders need more care

than the other children at their age. Treatments that are performed require more time, effort, and patience. This results in psychological distress, depression and anxiety and other physical and mental health problems in the parents. Parents also experience financial problems, that are costs for health, and lose their jobs. Parents of children with autism spectrum disorders feel the pressure of having to care for children with ASD.¹⁴

In this study, the burden can be influenced by several things, that is the majority of research subjects take care of their children without any support and assistance from others (83%). Mothers of children with ASD who raise their own children without the help of others, of course, will experience a heavier emotional and physical burden. According to Mak and Kwok, the welfare of parents who care for children with ASD is strongly influenced by the support from family, other friends or health professionals.¹⁵ This result also accordance with research by Picardi, 2018 that is social support also become one factor of caregiver burden.¹⁶ Research by Lerthattasilp also states that caregivers who spend more time with children with ASD will experience a heavier burden compared to caregivers whose duration of parenting is shorter.¹² Research by Alnazly also stated that caregiver burden also related to the difficulties task during caring children with ASD.¹⁷ Psychosocial support from others to assist in parenting is so necessary to prevent caregiver burden.¹⁸

The age of the child also affects the burden of mothers with ASD children. According to Lerthattasilp's research, the burden experienced by mothers as caregivers is influenced by symptoms or disabilities in children with ASD.¹² In children who are younger, the therapy process has not shown any improvement so that there are still many children's symptoms or disabilities. Children with ASD, apart from having a disability, are also accompanied by symptoms of aggressiveness and hyperactivity that take up the caregiver's time and also limit the caregiver's ability to socialize, causing a burden on the mother.¹⁹ Parents are also concerned about the lack of assistance from others in caring for children with ASD.²⁰ Lerthattasilp et al., also stated that the burden on mothers is also influenced by the length of time the child is diagnosed with ASD.¹² Children with an earlier age show an earlier time of diagnosis so that it supports the emergence of a caregiver burden on mothers. In addition, the burden that appears on the mother is also influenced by the mother's age. From the interview results, the older the mother, the mother feels worried about the future of the child with ASD because the mother feels that she is no longer able to care for and care for her child who has special needs. This psychological burden can trigger the burden on the mother. In addition, for mothers who are older, in terms of health, there are physical complaints, even though caregivers for children with autism require greater energy to cope with symptoms when the child is hyperactive, aggressive or emotionally irritable. With this condition, mothers of children with ASD experience a decrease in physical health which can also affect the emergence of burdens on mothers. The impact of the burden experienced by mothers of children with ASD can worsen the quality of life of mothers which in turn can affect the therapy process for children with autism spectrum disorders.^{21,22}

Conclusion

Mothers with ASD children experience a psychological burden during caring for ASD children. Psychosocial factors that affect the burden on mothers are the current age of the mother, the child's age and social support and assistance from the closest environment while caring for children with autism spectrum disorders. Psychosocial support and assistance from the environment are urgently needed to reduce the caregiver burden on mothers so that they can improve the outcomes of interventions and therapy for children with autism spectrum disorders.

Conflict of Interest

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article

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