

# Internal Self-Stigma and External Factors of Social Support with Burden in Families with Mental Retardation

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## Abstract

Mental retardation is one disability in the form of intellectual development deviations. This clinical condition is characterized by decline in cognitive, language, motoric and social abilities, this leads to lifelong dependence on families as *caregivers* and impacts to physical and psychological individuals, families and society. This cause a family burden. The purpose of this study was to find the relationship between self-stigma and social support with the burden of families of mental retardation sufferers. This study used an observational analytic method with a *cross-sectional* approach. The sample in this research is family members of mental retardation practitioners in Sidoharjo village, Jambon Subdistrict, Ponorogo Regency, East Java Province, Indonesia, amounting to 58 people selected by technique *purposive sampling*. Data collection using a questionnaire. Data were analyzed through univariate and bivariate analysis using the Spearman Rank test. The results of the bivariate analysis of the relationship between self-stigma and family burden were obtained  $p = 0.001$  and  $r = 0.429$ . This shows that there is a relationship between self-stigma and burden, the higher the self-stigma, the higher the burden of the family of mental retardation sufferers. The results of the bivariate analysis of the relationship between social support and burden were obtained  $p = 0.002$  and the value of  $r = -0.039$ . This shows that there is a relationship between social support and family burden, the higher the social support, the lower the burden of the family of mental retardation sufferers. The conclusions of this study is that there is a relationship between self-stigma and social support with the burden on families of mentally retarded patients.

**Keywords:** *Self Stigma, Social Support, Burden, Family Mental Retardation Patiens.*

## Introduction

Mental retardation is one disability in the form of intellectual development deviations that often occur in children. This clinical condition is characterized by a decrease in cognitive, language, motoric and social abilities. The highest incidence of mental retardation are in countries growing amount of 2.3% <sup>(1)</sup>. Riskesdas data in 2013 showed that 8.3% million of the population in the total population of Indonesia about 250 million people are mentally retarded. Figures mental retardation in East Java recorded 1462 cases, while levels of

mental retardation in East Java in 2013-2014 are a number of 6633 cases of the estimated total population of around 250 million, consisting of mild mental retardation and mental retardation 3994 cases were 2639 cases <sup>(2)</sup>.

The village is called the «Idiot Village», which is one of them is Sidoharjo Village, Jambon Subdistrict, Ponorogo Regency, East Java Province, Indonesia, this is because in the village there are many residents who suffer from mental retardation and other disabled people<sup>(3)</sup>. Of the five villages in Ponorogo called “Kampung Idiot”, the village that experienced the most mental retardation was Sidoharjo Village, Jambon Subdistrict, 138 people or 2.4% of the total population in 2018, which is 5714 residents<sup>(3)</sup>. Villagers in this village have many common limitations in reflecting on

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their lives, which have already happened since decades ago around 1970. This was caused by various factors, including poor nutrition, inadequate infrastructure and health services, the water consumed was very low in iodine. The large number of people who experience mental retardation in Sidoharjo village and four other villages in Ponorogo Regency, they live with normal communities around them <sup>(4)</sup>.

Mental retardation can give a good psychological impact for individuals, communities and families. The impact on the individuals include physical effects such as barriers to daily activities and psychological effects such as shame and low self esteem <sup>(5)</sup>. The impact on the family is shock, denial, rejection and the tendency to hide people with mental retardation due to low self-esteem <sup>(6)</sup> and an increase in family burden in treating lifelong dependence, fatigue, loss of jobs and economic needs become serious problems for families <sup>(1)</sup>. The impact on society is the stigma of being labeled as "Idiot Village" <sup>(7)</sup>. Impacts on families are shock, denial, rejection and tendency to hide mental retardation sufferers (PRM) due to low self-esteem <sup>(8)</sup> and increased family burden within treating lifelong dependence, fatigue, loss of work and economic needs is a serious problem for families in caring for PRM <sup>(9)</sup>.

The family is a set of several family members who live in one household in a consistent and close relationship, this creates a burden as a caregiver, the family burden is a response multidimensional to physical stress, psychological, emotional, social and related daily financial experience <sup>(10)</sup>. So that this family has a big responsibility, without the knowledge and support and the stigma of the family's self will have an effect on the burden <sup>(11)</sup>. Stigmatization of mental illness is now considered one of the most important problems facing mentally ill individuals caregiver. This poses a burden to caregivers, the burden of mental health problems increases globally. Stigmatization of mental retardation is now considered one of the most important problems facing families. This causes physical stress, psychological, emotional, social and related financial care experience so that it becomes a burden to the family <sup>(12)</sup>. The cultural value of placing caregivers at greater risk has an effect on self-stigma and exacerbates the burden. Because of their psychological stress, the stigma of caregivers is supported by the stigma of the community on their family and relatives. Public stigma affects the cognitive, affective and behavioral

family so that the family gave a negative assessment of him. This family's self-stigma leads to how individuals feel burdened by the feeling of having a disabled, stupid and strange family member. This self-stigma directly contributes to the experience of the caregiver's distress in this family <sup>(13)</sup>.

Internal factors family that is the self-stigma and external factors is social support that will affect the family burden in caring for Mental Retardation Patients. External factors are such as social support that will affect the family burden in treating Mental Retardation Patients. The role of caring for family members with mental disorders can have a negative psychological impact, and their physical, social health. Situations where primary caregivers do not have support from other family members to share caring can cause an increase in burden <sup>(14)</sup>.

The Aim of this research is to know the relationship between self-stigma and social support with the burden of families of mental retardation sufferers.

## Method

This research uses analytic survey design observational with *cross-sectional* approach. The populations in this study were healthy family members who had mental retardation in one village named Sidoharjo village, amounting to 138 families. The number of samples is 58 selected by technique *purposive sampling*. The sample choice based on inclusion criteria that is one of the family members healthy and care for people with mental retardation, able to read and interact well, families with ages over 18 years, staying one home with people with mental retardation of at least more than 6 months do treatment day to patient everyday, willing to be a respondent. Data collection used a *Multidimensional Scale of Perceived Social Support questionnaire* to measure social support, *Affiliated Stigma* to measure self-stigma and *The Informal Caregiver Burden Assessment* to measure family burden. Data were analyzed by univariate analysis and bivariate analysis with the Spearman Rank test.

## Results

### Univariate Analysis Results

The results of the bivariate analysis consisted of demographic data, social support distribution and load distribution.

**Table 1. Characteristics of Respondents by Age of Family and Patients**

	N	Mean	Median	Min-Max	SD
Family Age	58	39.98	41	18-65	13.31
Age Of The Patient	58	49.47	53	8-83	16.84

Based on the T right 1 above , the average family is 40 years old. As for patients, on average 49 years old.

**Table 2. Respondents Demographic Characteristics Based on Gender, Education, Occupation, Income, Marital Status, Relationship to Patients and Length of Care**

Variable	Category	Frequency	Percentage
Gender	Man	19	32.8
	Women	39	67.2
Education	Elementary school	48	82.8
	Junior high school	4	6.9
	High school	2	3.4
	No school	4	6.9
Work	Farm workers	39	67.2
	Farmer	3	5.2
	Civil servants	1	1.7
	Private	9	15.5
	Does not work	6	10.3
Income	< regional minimum wage	55	94.8
	> regional minimum wage	3	5.2
Marital Status	Married	50	86.2
	Sigle	7	12.1
	Widow	1	1.7
Relationship With Patients	Mother	8	13.8
	Father	3	5.2
	Child	13	22.4
	Relatives	34	58.6
Long Caring	1-5 years	1	1.7
	6-10 years	9	15.5
	> 10 years	48	82.5

Based on the second sentence above, it shows that most of the sexes are the most dominant, namely women with 39 people. Education is mostly primary schools with 48 people. Most of the jobs are farm laborers with 39

people. Most of the income is Rp. < regional minimum wage with 55 people. The most dominant marital status is married with 50 people. Most of the relationships with sufferers are brothers with 34 people. The duration of treatment is mostly > 10 years with a total of 48 people.

**Table 3 Univariate Tables**

Variable	Category	Frequency (f)	Percentage (%)
Self Stigma	High	27	46.6
	Medium	31	53.4
Social Support	Medium	26	44.8
	High	32	55.2
Burden	Weight	15	25.9
	Medium	40	69
	Light	3	5.2

Based on the third t above, it shows most of the respondents' self-stigma namely moderate with 31 people. Social support is mostly high with 32 people and the burden is mostly moderate with 40 people.

**Table 4 Bivariate Tables**

Variable	Category	Family expenses			r	p
		Weight	Is being	Light		
Self Stigma	High	12 (20.7%)	15 (25.9%)	0 (0%)	0.429	0.001
	Medium	3 (5.2%)	25 (43.1%)	3 (5.2%)		
	Light	6 (10.3%)	25 (43.1%)	2 (3.4%)		
Social Support	High	3 (5.2%)	27 (46.6%)	2 (3.4%)	-0.39	0.002
	Medium	12 (20.7)	13 (22.4%)	1 (1.7%)		

Based on the t- 4 above, the results show that the p value of self-stigma  $p = 0.001$ , the value of p-value for social support  $p = 0.002$ , this indicates there is a relationship between self-stigma and social support, the r value of self-stigma of  $r = 0.429$  indicates correlation positive with moderate strength. This shows that the higher the self stigma, the higher the burden. The r value of social support of  $r = -0.39$  shows a negative correlation with weak strength. This shows that the higher the social support, the lower the family burden of mental retardation patients in Sidoharjo Village, Jambon Subdistrict, Ponorogo Regency.

### Discussion

Stigma is a negative attribute of a phenomeno in a particular society or environment when an individual is ostracized or rejected <sup>(15)</sup>. In addition to economic

and material burdens, caregivers of people with mental illness are exposed to psychosocial challenges. Self-stigma is one of the psychological challenges that can be exacerbated by intrinsic or extrinsic factors <sup>(16)</sup>. Self-care stigma can negatively affect the nursing process and not only affect people who suffer but also families. It has a negative impact on the family support their economic and daily care, and relationships with family, well-being and health, so that family members cope with caregiver burden is very large <sup>(16)</sup>.

Research conducted by <sup>(17)</sup> refer to explained shortly stigma on individuals who internalized stigma from society. Three psychological response interrelated is cognition stigmatization (perception of competence and the value is lower than their counterparts because internalization

of stigma), affective (feeling of shame, despair, and shame as a result of the status stigma is internalized), and behavior (behavioral reactions as a result of internalized stigma such as withdrawal and slander). Caregivers of people with mental illness have adequate stigma and can have stronger pressure so that they feel a greater burden in the care process. They feel embarrassed because having a family member who has a temporary mental illness is obliged to take care of him. Thus, these caregivers can experience feeling tense and depressed, a sense of burden and concern in caring for treatment, and experiencing stigma. It will worsen and increase the burden of care. The caregiver's self stigma is also influenced by the demographic data of the respondents, namely age and sex. This is in accordance with the research conducted by <sup>(18)</sup> that young age with female sex in internalizing self-stigma affects their psychological problems. Besides that, it is associated with living in the countryside, low education level, low income and long duration of treatment.

Research conducted by <sup>(19)</sup> in 30 mothers with mentally retarded children and 30 mothers with normal children. Obtained differences in social support obtained and perceptions of their burden. Parents of children with mental retardation experience high levels of emotional, financial and physical stress. Mothers of children with disabilities have a higher perception of the economic situation and adequacy of income and social support, adding to the burden on their families. Other research conducted by <sup>(20)</sup> regarding the relationship of social support to dementia caregivers in the United States, the burden felt by families in caring for family members who have high dementia results in social support can reduce the burden subjectively. Other research conducted by <sup>(21)</sup> in 181 mothers in Korea who have children with disabilities, it was found that most mothers experienced a high burden, especially in financial matters and increased costs related to their child's disability. The results show that social support can reduce this burden.

Social support is a broad term covering various constructs, including perceptions of support and acceptance of supportive behavior <sup>(19)</sup>. Sidoharjo Village The Jambon subdistrict's observation has a program as a form of social support given to people with mental retardation, namely the Rising Sidowayah Forum (FSB). This organization was founded by the public because they saw

the personality of so many mental retardation sufferers. Its activities are not only about food, clothing, shelter, but also about health, self-development, and other empowerment issues, as well as facilitating parties to care about the problems experienced by mental retardation residents. This is proof that their social support is high <sup>(20)</sup>.

## Conclusion

Self-stigma is found to be moderate and high social support that can affect the family burden in treating Mental Retardation Patients. The higher the self stigma the more heavy the burden, while the higher the social support the lower the burden. In this study, it is expected that families can reduce self-stigma and increase social support through better and more intimate relationships with friends, neighbors and society.

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