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Original Research

THE CORRELATION BETWEEN STIGMA AND FAMILY BURDEN IN CARING FOR PEOPLE WITH MENTAL DISORDERS

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ABSTRACT

Introduction: South Sulawesi has a high prevalence of mental disorders, affecting 8.8% of households. However, limited public awareness about mental health perpetuates stigma toward individuals with mental disorders and their families, significantly increasing the burden on caregivers. This study aims to identify the relationship between stigma and the caregiving burden experienced by families of individuals with mental disorders at Dadi Regional Special Hospital in South Sulawesi Province.
Method: This study is a quantitative study with a Cross-Sectional research design. The dependent variable is family burden and the independent is stigma. The sampling technique used was purposive sampling involving 94 respondents using the Stigma Items questionnaire from SCAN and the Zarit Burden Interview (ZBI). Data analysis included univariate analysis to outline frequency distributions and percentages of the variables, alongside bivariate analysis to assess the correlation between stigma and family burden through the Spearman rank correlation test.
Results: The results indicated that over half (58.5%) of families reported low stigma, while 51.1% experienced a mild to moderate burden. Statistical analysis using the Spearman correlation test revealed a significant relationship between stigma and family burden ($p = 0.000 < 0.05$). The correlation coefficient ($r = 0.522$) reflects a strong positive relationship, suggesting that increased stigma correlates with higher family burden among those caring for individuals with mental disorders.
Conclusions: There is a strong correlation between stigma and family burden in caring for people with mental disorders at Dadi Regional Special Hospital in South Sulawesi Province.

Keyword: family burdens; mental disorders; stigma

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1. INTRODUCTION

Mental health is a fundamental necessity for every individual. However, it remains a significant health issue globally, as evidenced by phenomena observed in China, which indicate that stigma towards individuals with mental disorders arises not only from societal perceptions but also from internalized beliefs, commonly referred to as self-stigma. Families of individuals with mental health conditions often withdraw from social interactions due to concerns regarding potential complications arising from the behaviors of their affected family members, leading to self-isolation (Liu et al., 2020). A similar situation is evident in Indonesia, where the prevalence of severe mental disorders, such as schizophrenia, has reached approximately 400,000 individuals or 1.7 per 1,000 of the population (Riskesdas, 2018). The high incidence of mental health issues correlates with the stigma experienced by the families of those affected (Al Wasi et al., 2021). One prevalent form of stigma involves the perception that mental disorders are hereditary, prompting families to avoid social contact and further isolate themselves (Agustang et al., 2021). This phenomenon is also observed in South Sulawesi Province, which has one of the highest prevalence

rates of mental disorders in Indonesia at 8.8% per 1,000 households(Riskesdas, 2018). Preliminary observations at the Psychiatric Polyclinic of Dadi Regional Special Hospital in South Sulawesi revealed that 3 out of 5 interviewed families reported experiencing stigma related to their family members' conditions.

Stigma can significantly influence the psychological burden experienced by families who serve as caregivers for individuals with mental disorders. Indeed, the overall burden of caregiving can act as a primary catalyst for the development of depression among family members (Lespine et al., 2023). The same study reveals that nearly half of the participants (44.3% or 170 individuals) reported experiencing a moderate to severe caregiving burden (Lespine et al., 2023). Additionally, another study found that approximately two-thirds of primary caregivers reported experiencing a high level of caregiving burden (Banerjee et al., 2024). This finding is consistent with research conducted in China, which indicates that the symptoms of depression experienced by family members are exacerbated by the stigma they encounter as caregivers (Zhou et al., 2018).

Beyond psychological or mental burdens, he types of burdens experienced by families include subjective burdens, which refer to the emotional and psychological experiences, feelings, and perceptions of caregivers related to their caregiving roles (Paruk & Ramdhial, 2018). On the other hand, objective burdens pertain to the tangible impacts of caregiving demands and encompass the practical and concrete aspects of care provision that are assessed externally, such as economic factors (Chisholm et al., 2019). The burden felt by the family due to stigma is included in the subjective burden, namely the social and psychological burden, especially in dealing with community stigma regarding their family members who suffer from mental disorders (Novian et al., 2020). The presence of people with mental disorders as a family member is already a stressor for the family, especially if coupled with the stigma given by the community (Suilia, 2021). The burden caused by stigmatization will have an impact on the difficulty of the family in handling people with mental disorders care comprehensively due to the people with mental disorders's attitude that can endanger the community environment which certainly raises family concerns (Ibad et al., 2021). Therefore, the family must be able to overcome stigmatization and manage the burden they feel well in order to provide optimal care to the patient because the family is the main caregiver of people with mental disorders (Nasriati, 2020).

In several studies that have been conducted from 2020 to 2023, it shows that there is a relationship between high stigma and the burden felt by families who have family members with mental disorders (Ebrahim et al., 2020; 2020; Wang et al., 2023). From some of these studies, it can be concluded that there is a significant relationship between stigma and family burden in caring for people with mental disorders. however, in Indonesia itself, this research is still very limited and has never been conducted in South Sulawesi Province. Therefore, it is necessary to conduct further research to compare the situation between different regions.

Based on the results of preliminary observations at the Psychiatric Polyclinic of the Dadi Regional Special Hospital of South Sulawesi Province in February 2023, it shows that there are 3 out of 5 families who have been interviewed claiming to still experience stigmatization. The family stated that they had often experienced stigmatization when they were in the community. In addition, one family also stated that stigma did not occur in their environment and there was no form of discrimination from the community, but with the condition of their family members suffering from mental disorders, the family chose to limit socialization with the community. So it can be concluded that families feel worried about the views of the community and it is also included in the stigma that families do to themselves.

From the initial observations that have been made, it can be seen that the phenomenon of stigma is still quite high in the community. This will certainly have a negative impact on the family and will be a burden that continues to be borne by the family. Therefore, by identifying the relationship between stigma and family burden, researchers hope that the stigma felt by families can be overcome or reduced with appropriate coping management, as well as the burden that can be felt by families at any time. Therefore, the purpose of this study is to identify the relationship between stigma and family burden in caring for People with mental disorders at the Dadi Regional Special Hospital of South Sulawesi Province.

2. MATERIALS AND METHODS

2.1 Design

Quantitative descriptive research using a cross-sectional approach.

2.2 Population and sampling

This research was conducted at the Psychiatric Polyclinic of the Dadi Regional Special Hospital of South Sulawesi Province with a research population of 1461 people which is the number of visits to the Psychiatric Polyclinic in January 2023. However, the population comprises not only the family members of the patients but also the patients themselves, friends, and distant relatives. The sample in this study was 94 family members who care for people with mental disorders, specifically primary caregivers. This sample size was determined using Slovin's formula with a selected margin of error of 10% (0.1). Additionally, the sampling method employed was purposive sampling, based on the following criteria:

a. Inclusion criteria : One Family Member who come to the psychiatric clinic of the Dadi Regional Special Hospital of South Sulawesi Province, Living in the same house with people with mental disorders, the main caregiver of the

b. people with mental disorders, and Able to read and write
c. Exclusion criteria : Family member who experience cognitive impairment and Families who are not willing to be respondents in the study

2.3 Variables

This study used 2 variables, namely dependent and independent variables. The dependent variable in this study is family burden and the independent variable in this study is stigma.

2.4 Instrument

The measurement of Family Burden was carried out using the Zarit Burden Interview (ZBI) Instrument which has been available in Indonesian in the research of (Al Wasi et al., 2021) and has been tested for validity and reliability by (Afriyeni & Sartana, 2017)with an Alpha Cronbach coefficient value of 0.907 (Al Wasi et al., 2021). This Instrument consists of two sections. The first section addresses personal stress, which describes the experiences perceived by family members (items 1, 4, 5, 8, 9, 14, 16, 17, 18, 19, 20, and 21). The second section focuses on role stress, which refers to the stress caused by role conflict or caregiver burden (items 2, 3, 6, 7, 11, 12, and 13). The Instrument comprises 21 questions measured using a Likert scale (1-5), with the response options defined as follows: 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, and 5 = Always. Family burden is categorized into four levels and the scoring range is from 0 to 88, with the following burden levels; no to mild burden (0-20), mild to moderate burden (21-40), moderate to severe burden (41-60), and severe burden (61-88). Stigma was measured using Stigma Items (SI) from SCAN (Schedule for Clinical Assessment in Neuro Psychiatry) or what can also be referred to as the Family Interview Schedule (FIS). Initially, this instrument was only used to assist clinicians in identifying stigma in families of schizophrenia patients with 94% accuracy that has been valid (p = 0.021) and reliable with a Cronbach alpha score of 0.786 (Irawati & Irmansyah, 2005). However, it has now been used to measure similar effects on families caring for family members with other mental illnesses and has been tested for validity and reliability (Duman et al., 2022). The instrument consists of 9 dimensions: self-esteem (items 2, 3, and 5), stereotypes (item 7), discrimination (items 1 and 9), shame (item 11), guilt/blame (items 8 and 14), isolation (item 10), avoidance behavior (item 6), depression (item 13), and helping behavior (items 4 and 12). In total, there are 14 questions rated on a Likert scale of 0 = never, 1 = occasionally, 2 = often, and 3 = always. The total score for the stigma variable is categorized into two groups: high stigma and low stigma. High stigma is determined based on a cut-off point of ≥ mean (10.73), while low stigma is defined as < mean (10.73).

2.5 Procedure

Data were collected directly by distributing questionnaires in the Psychiatric Polyclinic of the Dadi Regional Special Hospital of South Sulawesi Province. Family's who agreed to participate in this research were asked to fill out an informed consent form. Data collection was caried out for 1 month in February 2023. In collecting data, the researcher employed the following steps. First, The researcher requests permission to conduct the research from the Head of Training Hospital Special District (RSDKD) Dadi Province South Sulawesi to carry out the research by obtaining data at the Psychiatry Ward. After obtaining permission to collect data, the researcher visited the psychiatry ward to gather data and obtained data from the psychiatry ward. This process began by seeking family approval through informed consent, which was signed if they agreed to participate in the study. After that, the researcher conducted interviews regarding the questions in the questionnaire with enumerators who were nursing students. These students had previously undergone a consensus on the questionnaire with the families accompanying individuals with mental disorders in the Mental Health Outpatient Clinic. After the questions in the questionnaire were filled out and answered, the researcher expressed gratitude to the families of individuals with mental disorders for their assistance and participation in this study. All collected data were then processed in the data processing stage. Last, the researcher compiled the results and conclusions of the study based on the data that had been collected.

2.6 Statistical Analyses

Data analysis conducted in this study used univariate analysis which aims to describe the frequency distribution and percentage of all research variables and also bivariate analysis to analyze the relationship between stigma and family burden using the Spearman rank correlation test (Heryana, 2020).

2.7 Ethical Clearance

Researchers conducted an ethical feasibility test at Health Research Ethics Committee Faculty of Public Health, Hasanuddin University with number 3934/UN4.14.1/TP.01.02/2023

3 RESULT

Based on table 1. shows the results of the frequency distribution of the demographic characteristics of families caring for individuals with mental disorders at Dadi Mental Hospital's Psychiatric Polyclinic. The majority of caregivers are adults aged 18-60 years, comprising 90.4% (85 individuals). The gender distribution indicates that most caregivers are female, totaling 84.0% (79 individuals). Nearly all respondents identify as Muslim (97.9%), with Bugis being the predominant ethnicity at 44.7%. Educationally, most respondents have completed high school (53.2%, or 50 individuals). Employment data reveals that over half (57.4%) of the respondents

Table 1. Instrument Zarit Burden Interview (ZBI)
Ket: n=Frekuensi, %=Persentase

Section	Interpretation	Questions number
1	The first section addresses personal stress, which describes the experiences perceived by family members	1, 4, 5, 8, 9, 14, 16, 17, 18, 19, 20, and 21
2	The second section focuses on role stress, which refers to the stress caused by role conflict or caregiver burden	2, 3, 6, 7, 11, 12, and 13

Table 2. Instrument Stigma Items (SI) from SCAN (Schedule for Clinical Assessment in Neuro Psychiatry)

Dimensions	Interpretation	Questions number
1	Self-esteem	2,3,5
2	stereotypes	7
3	discrimination	1,9
4	Shame	11
5	Guilt/blame	8,14
6	Isolation	10
7	Avoidance behavior	6
8	Depression	13
9	Helping behavior	4,12

are unemployed. Regarding familial relationships, 30.9% (29 individuals) of caregivers are mothers of those with mental disorders. Furthermore, more than half of the respondents earn below the minimum wage (<Rp3,385,145), accounting for 60.6% (57 individuals). The study also found that a significant portion of individuals with mental disorders, specifically 38.3% (36 individuals), have experienced their conditions for a duration of 5-10 years.

Table 2 shows that a majority of families caring for individuals with mental disorders at Dadi Mental Hospital in South Sulawesi experienced low stigma, with 56 families (59.6%) reporting this, while 38 families (40.4%) reported high stigma. Regarding family burden, 48.9% of families reported a no to mild burden, 33% experienced a mild to moderate burden, and 17% (16 families) faced a moderate to severe burden, with one family classified as experiencing a severe burden.

Based on table 3. from the results of statistical analysis using the spearman correlation test, the p value = 0.000 was obtained. The p value is smaller than p (0.05), which means that there is a significant relationship between the stigma variable and family burden. Then the correlation coefficient is (r) = 0.522 which shows a strong correlation level which is included in the range (0.51-0.75). The value of r also shows the direction of the relationship between the two variables, which if positive, is unidirectional, that is, the higher the stigma, the higher the family burden felt by families caring for people with mental disorders, and vice versa.

Table 3. Frequency Distribution of Respondent Characteristics (n = 94)

	Characteristic	n	%
Age	Adult: 18-65 years old	85	90,4
	Elderly: >65 years old	9	9,6
Total		94	100
Sex	Female	79	84
	Male	15	16
Total		94	100
Religion	Islam	92	97,9
	Christian	2	2,1
Total		94	100
Ethnic Group	Bugis	42	44,7
	Makassar	28	29,8
	Bugis Makassar	7	7,4
	Others	17	18,1
Total		94	100
Education	No Level	5	5.3
	Elementary School	14	14,9
	Junior High School	6	6,4
	Senior High School	50	53,2
	Diploma	4	4,3
	Bachelor	15	16
Total		94	100
Job	Employment	40	42,6
	Unemployment	54	57,4
Total		94	100
Relationship	Father	8	8,5
	Mother	29	30,9
	Daughter/Soon	15	16
	Husband	4	4,3
	Wife	8	8,5
	Older Brother/Sister	22	23,4
	Younger Brother/Sister	8	8,5
Total		94	100
Family Income	<Minimum wage (Rp3.385.145)	57	60,6
	≥Minimum wage (Rp3.385.145)	37	39,4
Total		94	100
Duration of Mental Illnes	<5 Years	34	36,2
	5-10 Years	36	38,3
	>10 Years	24	25,5
Total		94	100

Note: n=Frequency, %=Percentage

4 DISCUSSION

In this study, the majority of respondents were female, aged between 18 and 65 years, with a highest level of education being high school, and were mothers of the patients. This demographic indicates that many family members are adults, reflecting maturity and cognitive capability to participate in decision-making as primary caregivers (Lin et al., 2021). Families that are mature and have at least a high school education may possess greater knowledge and information related to health issues (Raghupathi & Raghupathi, 2020). This background has the potential to reduce the burden and stigma experienced, as families are likely to implement adaptive coping mechanisms in caring for individuals with mental disorders (Jumaisah et al., 2023).

Table 4. Frequency Distribution of Stigma and Family Burden (n = 94)

	Characteristic	n	%
Stigma	Low Stigma	56	59,6
	High Stigma	38	40,4
Total		94	100
Burden	No to mild Burden	46	48,9
	Mild to moderate Burden	31	33
	Moderate to severe Burden	16	17
	Severe Burden	1	1,1
Total		94	100

Note: n=Frequency, %=Percentage

Table 5. The Correlation between Stigma and Family Burden of Caring (people with mental disorders) at Dadi Regional Special Hospital, South Sulawesi Province (n = 94)

Stigma	Family Burden								Total		*r*	*p-value*
	No to mild		Mild to moderate		Moderate to severe		Severe					
	n	%	n	%	n	%	n	%	n	%		
Low	35	63,6	16	29,1	3	5,5	1	1,8	55	58,5	0,522	0,000
High	11	28,2	15	38,5	13	33,3	0	0,0	39	41,5		
Total	46	48,9	48	51,1	0	0,0	0	0,0	94	100		

**Spearman Correlation*

Furthermore, the duration of patient care is also related to the stigma and burden experienced by families. According to Edwar et al., (2021) family stress tends to increase during the initial years of caring for individuals with mental disorders; however, over time, families often find ways to adapt to their circumstances. In this study, most families had been caring for patients for a duration of 5 to 10 years, which correlates with a decrease in perceived stigma and burden. According to stress adaptation theory, caregivers gradually acquire various nursing skills over time and adapt to the pressures associated with caregiving tasks (Liu et al., 2020). Thus, it can be concluded that these families have accepted the condition of their family members and their surrounding environment while developing effective coping mechanisms through various strategies to address the challenges associated with caring for individuals with mental disorders.

The majority of families also have low incomes, with many caregivers lacking employment. However, meeting the needs of individuals with mental disorders requires significant financial resources. Consequently, it is not surprising that families experience financial difficulties (Phillips et al., 2023), particularly among low-income communities (Javed et al., 2021). This economic burden is categorized as an objective burden because it pertains to the tangible impacts of caregiving demands and encompasses the practical and concrete aspects of care provision that are assessed externally (Chisholm et al., 2019). Nevertheless, this does not pose a significant burden for caregivers due to government programs that cover the costs of mental health treatment, commonly referred to as the JKN-KIS program. This program ensures coverage for consultations, medications, rehabilitation services, and even referrals to hospitals for further treatment (Purwanti, 2021). As a result, families with incomes below the minimum wage are supported and relieved from financial strain due to this program.

In addition to the objective burden, there is also a subjective burden that refers to the emotional and psychological experiences, feelings, and perceptions of caregivers related to their caregiving roles (Paruk & Ramdhial, 2018). Similar to the objective burden, the majority of families do not experience significant levels of subjective burden, particularly those who have cared for individuals with mental disorders for an extended period. Research conducted by Mislianti et al., (2021) indicates that the duration of care for individuals with mental disorders influences the families' feelings of shame. According to interview findings, families reported experiencing feelings of shame primarily during the initial stages of caregiving; over time, they became accustomed to their situation and learned to disregard negative comments from the community (Mislianti et al., 2021). Therefore, it can be concluded that families do not experience a subjective burden in terms of feelings of shame associated with their caregiving responsibilities. Similarly, the stigma experienced by families is also influenced by feelings of shame, which aligns with research indicating that the majority of families experience low levels of stigma.

Additionally, some families report experiencing mild to moderate burdens. This finding is consistent with research conducted by Afriyeni & Sartana, (2017), which indicates that the majority of families, specifically 65 individuals (43.3%), perceive their burden from caring for individuals with mental disorders to fall within the no to mild category. According to their findings, this phenomenon may arise because most families view the pressures or burdens associated with caregiving as a responsibility that they must fulfill, reflecting their

beliefs about their roles and responsibilities in this context (Afriyeni & Sartana, 2017).

This study analyzed the relationship between stigma and the burden on families of people with mental disorders in the Dadi Mental Hospital of South Sulawesi Province using the spearman rho test statistical test with a p-value of 0.000 <0.05, so Ho is rejected H1 is accepted, meaning that stigma has a significant relationship with the burden on families caring for people with mental disorders in the Psychiatric Polyclinic of the Dadi Mental Hospital of South Sulawesi Province. This is in line with the results of research by Ebrahim et al., (2020) which also found a significant relationship between stigma and burden in families who have family members with mental disorders in Turkey. This research is also supported by the results of research by Wang et al., (2023) conducted in the Xinjin area, China which shows that there is a relationship between affiliation stigma and the burden of caregiving in families caring for people with mental disorders.

The low stigma and mild to moderate burden experienced by families may also be influenced by societal phenomena. One such phenomenon is the abandonment of individuals with mental disorders, which includes not only neglecting their care and confining them at home but also allowing them to live on the streets or even leaving them in hospitals for years (Kemenkes, 2017). As a result of this phenomenon, the stigma experienced by families is likely to diminish because they are no longer living with or caring for individuals with mental disorders. Consequently, feelings of shame, sadness, or worry may decrease as they are relieved from the responsibility of providing care for the patient. Similarly, the burden on families becomes lighter since the role of informal caregivers includes monitoring medication, serving as a liaison between healthcare providers and the family, early identification of signs of relapse, managing daily tasks such as self-care, providing meals, and ensuring the safety of the individual (Silaule et al., 2024). Thus, the burden is lessened because they are no longer required to care for someone with a mental health condition. Research has shown that caring for a family member with mental health issues places families at high risk for experiencing negative emotions such as anger, aggression, frustration, low self-esteem, constant worry, and feelings of helplessness (Lamont & Dickens, 2021). Therefore, for families that allow their relatives to live on the streets or leave them in hospitals for years, their roles diminish significantly, consequently reducing both their burden and the risk of experiencing negative impacts during the caregiving process.

One limitation of this study is the minimal sample size, which is insufficient relative to the total population visiting the psychiatric policlinic at Dadi Regional Special Hospital. The population includes not only family members but also patients, friends, and distant relatives who do not meet the research criteria. Future studies should focus on sampling only caregivers of individuals with mental disorders to ensure a more representative sample.

5 CONCLUSSION

Based on the results of research that has been conducted at the South Sulawesi Provincial Psychiatric Hospital about stigma and family burden in caring for people with mental disorders with a total sample of 94 people, it can be concluded that more than half of the families experience low stigma in caring for people with mental disorders at the Dadi Psychiatric Hospital of South Sulawesi Province, some of the families feel a mild to moderate family burden in caring for people with mental disorders at the Dadi Psychiatric Hospital of South Sulawesi Province, and there is a significant relationship between stigma and family burden in caring for people with mental disorders at the Dadi Psychiatric Hospital of South Sulawesi Province.

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