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Family Load Caregiver (Studies in Families of People with Mental Disorders in the Work Area of the Kebasen Health Center, Banyumas Regency in 2020)

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Abstract

People with mental disorders generally experience disability in various ways, so they really need their families as caregivers. Those conditionscreates a burden for his family, both subjective and objective burdens. The purpose of the study was to describe the burden on the family as a caregiver who takes care of family members with mental disorders in the working area of the Kebasen Health Center.This type of research is descriptive analytic research. The number of samples as many as 45 families who have family members with mental disorders and taken by purposive sampling technique. Collecting data using a questionnaire. Data analysis was carried out by univariate analysis in the form of a frequency distribution.The results of the study prove that sall respondents experience the burden of caring for family members who have mental disorders. The highest burden was at the moderate level, as many as 29 people (64.44%). Next are heavy loads as many as 10 people (22.22%) and lastly light loads as many as 6 people (13.33%). The difference in caregiver burden lies in the level of perceived burden.

Keywords
family burden; mental disorder; caregiver.

I. Introduction

Mental health is a significant health problem worldwide and always affects the lives of individual sufferers and those around them (Rukmini & Syafiq, 2019). Mental health disorders need serious attention considering the number of cases is quite large. Agustina & Handayani (2017) stated that around 450 million people suffer from mental and behavioral disorders worldwide. It is estimated that one in four people will suffer from a mental disorder during their lifetime. According to the Ministry of Health of the Republic of Indonesia (2019), the prevalence of severe mental disorders in the Indonesian population is 1.7 per mile. The most severe mental disorders in DI Yogyakarta, Aceh, South Sulawesi, Bali, and Central Java. Furthermore, Riskesdas also stated that the prevalence of emotional mental disorders in the population of Central Java.

Mental disorders reveal a complex picture that injures human life like a double edged sword. On the one hand, the disorders suffered and the side effects of their treatment have a negative effect on emotions, cognitive abilities, memory, problem-solving and decisionmaking abilities, social skills, communication skills, and other areas of ability. On the other hand, stigma that leads to discrimination, takes away their opportunity to achieve and maintain life goals. Complete intervention is needed to overcome both problems. (Sitepu, F. et al. 2020)

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People with mental disorders usually have a real disability at the level of daily functional abilities, so they need help and assistance in meeting their life needs on other parties, especially family members. This can have an impact on service providers, especially families of sufferers who act as service providers or caregivers (Fitrikasari, et al, 2012).

Caregiverare people who help the daily activities of individuals who need treatment assistance such as sick people and children (Alifudin & Ediati, 2019). Being a caregiver is certainly not easy because in that role a person or group of people must at least be ready to exert all their energy, both physically and mentally to help people in need. Therefore, a caregiver needs preparation to accept all the risks that exist, one of the risks of being a caregiver is being susceptible to stress due to negative emotions.

Caregiver People with mental disorders are generally carried out by the family of the sufferer. Various impacts can appear on the family during their role as caregiver. Pangandaheng (2018) states, in general the impact felt by families with family members experiencing mental disorders is the high economic burden, family emotional burden, stress on disturbed patient behavior. Mental disorders are considered a disease due to sin from their families and are a disgrace to clients and their families, so there are still many families who hide their family members who have mental disorders, families feel ashamed, disappointed and hopeless.

Research on 114 caregivers of patients with severe mental disorders stated that they experienced a burden during treatment, and the level of caregiver burden was moderate (Sapouna et al., 2015).

This study generally aims to describe the burden on families caring for family members with mental disorders in the working area of the Kebasen Health Center. While the specific objectives are: to describe the caregiver's characteristics which include age, gender, education, and economic status, to describe the burden felt by the family as a caregiver.

II. Research Methods

The type of research in this research is descriptive research. The variable in this study is the burden on the family as caregiver. The subjects of this study were families who became caregivers for people with mental disorders in the working area of the Kebasen Health Center. The number of samples as many as 45 people were taken by purposive sampling technique. The research instrument used a questionnaire. Data analysis used univariate analysis in the form of a frequency distribution.

III. Results and Discussion

The research data regarding the characteristics of the respondents are presented in the following table:

Table 1. Characteristics of Respondents

No.	Characteristics	Frequency	%
1.	Gender		
	Woman	28	62.22
	Man	17	37.78
	Amount	45	100
2.	Age		
	Teenager	1	2.22
	Early Adult	27	60.00

	Late Adult	10	22.22
	Early Elderly	7	15.56
	Amount	45	100
3.	Education		
	Base	28	62.22
	Intermediate	17	37.78
	Tall	0	0.00
	Amount	45	100
4.	Economic Status		
	Low	24	53.33
	Currently	18	40.00
	Tall	3	6.67
	Amount	45	100

The data presented in Table 4.1 shows that most of the respondents were in early adulthood, as many as 27 people (60.00%), and the lowest distribution was respondents in early elderly age with a total of 7 people (15.56%). In terms of gender, respondents were dominated by women, as many as 28 people (62.22%), while 17 people (37.78%). So the caregivers in this study were dominated by women.Women play an important role as health leaders and provide care for sick family members. A woman is more at home, while a man's job is to earn a living (out of the house), so many care givers are female (Friedman, Bowden & Jones, 2010).

From the aspect of education, most of the respondents have low education with a total of 28 people (62.22%), followed by secondary education as many as 17 people (37.78%). The economic status of the respondents in this study were mostly low, namely 24 people (53.33%). Next is the medium economic status as many as 18 people (40.00%), and high as many as 3 people (6.67%).This is also in accordance with research

The description of caregiver characteristics in this study is in accordance with the research Rinawati and Sucipto, (2017), regarding the effect of the burden on the stress experienced by families in caring for patients with mental disorders, it was found that some caregivers of mental patients were dominated by female sex, adult age, low education and low economic status. Ralevic et al., (2015) stated that gender, socioeconomic status are mediators of caregiver burden in addition to family relationships, social support, coping strategies, health status, culture and other life events.

The caregiver burden in this study was grouped into 4 (four) categories, namely no burden, light load, moderate burden, and heavy burden. The results of research on caregiver burden can be seen in table 4.2 below:

Table 2. Caregiver Load

No.	Load Rate	Frequency	Percentage
1.	Light	6	13.33
2.	Currently	29	64.44
3.	Heavy	10	22.22
	Amount	45	100

The data in Table 4.2 shows that of the 24 respondents studied, the highest burden group was at the moderate level, with a total of 29 respondents (64.44%). For other loads, 6 people (13.33%) were light and 10 people had heavy loads (22.22). So, all respondents feel the burden of being a caregiver in caring for family members who suffer from mental disorders. The difference lies only in the level of perceived load.

Family is the closest party to a person with mental disorders, both physically and psychologically. Correspondingly, families are also potentially most affected by. The people who are most affected by the presence of mental patients are the family, because the family is the person who lives and takes care of the patient. If one of the family members has a mental disorder, the family will feel sad, share the pain, confusion in caring for, ashamed to face the stigma that exists in society, and ashamed to socialize. This is called the family burden (Stuart, 2013).

The results showed that all respondents experienced different levels of burden in caring for their family members with mental disorders. The highest burden was at the moderate level, as many as 29 people (64.44%). Next is a heavy load of 10 people (22.22) and the last is a light load of 6 people (13.33%). So the burden experienced by the respondents of this study tends to be moderate.

The burden felt by respondents in caring for family members who have mental disorders is in accordance with the opinion of Fitrikasari, et al (2012) that people with mental disorders can have an impact on service providers, especially families of sufferers who act as service providers or caregivers. Likewise, Fontaine (2009) who argues that family burden is the level of family distress experience as an effect of the condition of family members, which can cause increased emotional and economic stress from the family.

The burden felt by respondents in caring for family members with mental disorders strengthens the results of previous studies. Rafiyah and Sutharangsee's research (in Darwin, Hadisukanto, Elvira, 2013) shows that the burden of care has an impact on emotional, physical health, social life, and financial status as a result of caring for sick people. They view the burden as a result of the caregiver's subjective perception when caring for patients. The results of the research by Fitrikasari, et al (2012) also showed that the family felt burdened by the patient's condition. The sequence of domains that have the most role in caregiver burden is the impact on feeling comfortable, the severity of the problem faced, the impact of relationships with other people, appreciation of the role of care and the impact on the quality of marital relationships. The same thing was found in the results of Widyastuti's research (2011) which identified 4 burdens, namely: 1) physical burden; 2) psychological burden; 3)); economic burden, and 4) social burden.

The burden experienced by caregivers is related to lack of knowledge, emotional burden, physical burden, treatment, financial burden, social burden, health services and government support. (Nenobais, Jatimi and Jufriyanto, 2019).According to research by Von Kardorff et al., (2016), stated the burden experienced by caregivers of schizophrenia and affective disorders, namely:

1. Uncertainty
   Most caregivers experience uncertainty and ambivalence about the disease, treatment and the patient's future.
2. Unconsciousness
   The majority of caregivers do not have sufficient information about the disease and its treatment.
3. Emotional burden
   The emotional burden experienced is sadness, depression, feelings of shame, fear, anxiety, worry, guilt and anger. Most caregivers experience these feelings at a high level, which can affect their own mental health.
4. Stigma and blame
   The majority of caregivers show concern and distress about stigma and blame from extended family and relatives.

5. Financial burden
   The financial burden is one of the most important burdens conveyed.
6. somatic load
   Physical burdens experienced include somatic complaints, lack of energy, sleep disturbances, feelings of fatigue and exhaustion.
7. Routine restrictions
   Some caregivers stated that they experienced limitations in carrying out daily activities and letting go of things they could previously enjoy.
8. Disruption of routine
   Many caregivers experience disruption in their daily life and way of life. Increased workload, responsibilities in daily life, family duties and selflessness.
9. Dissatisfaction with family and relatives. Some of the causes include lack of help and support, lack of empathy from family and relatives.
10. The problem of patient adherence to treatment.
    The problems experienced are patient compliance with taking medication and timeliness of taking medication, as well as difficulty in providing medication.
11. Problems with health services and government support
    Several participants mentioned the lack of support and services, which refers to the availability of health services, insurance problems and transportation difficulties.

The various burdens experienced by caregivers can be understood because the process of caring for and healing people with mental disorders generally requires a fairly long process. Therefore, it takes a lot of time, effort and money to treat people with mental disorders.

Various actions that must be taken by families in caring for people with mental disorders will be a separate problem faced by families in caring for. If the family is burdened, the family may not be able to take care of the patient properly. The family's low economic status and the client's condition which makes it impossible to work add to the burden of caring for patients. This is supported by the opinion of Setiawan and Wulandari (2016) that the objective burden is a problem related to the implementation of patient care, which includes: housing, food, transportation, treatment, finance, and crisis intervention. During treatment, the family experiences an economic burden, the family's low economic status and high medical costs are one of the inhibiting factors experienced by the family. The method of care provided by the family in this study is to be slow, not harsh, which means that the treatment must be gentle. Previous research conducted by Fadli & Mitra (2013) obtained results on how to provide care carried out by families, it is recommended not to deal with sufferers harshly because it can cause the patient's condition to get worse.

The burden experienced by caregivers in caring for family members with mental disorders is increasing with social reactions that are often negative towards people with mental disorders and their families. In this context, the social environment usually has a negative attitude towards people with mental disorders, such as exclusion from association, ridicule, discrimination, and so on. In line with that, people also often regard mental disorders as a disgrace, something to be ashamed of. This kind of stigma is not only attached to people with mental disorders, but also to their families. What's more, the stigma often remains even though people with mental disorders have been declared cured. This proves that the stigma against people with mental disorders is difficult to remove, even though the sufferer has been declared cured.

The description above is in line with Rafiyah's opinion (2011) that the emotional burden felt by almost all family members, including sadness and shame due to uncontrolled patient behavior, is feared to endanger the environment and worry about the patient's future. This can increase the emotional burden on the family.

So it is clear that there are many burdens that can be placed on families who have members with mental disorders. In other words, the burden on the family as a caregiver is not light. The results of the WHO research in 2018 showed that mental disorders resulted in a fairly large burden of 8.1%. Although the problem of mental disorders does not cause death, it causes deep suffering for each individual and a heavy burden for the family, both physically, mentally, and economically because sufferers no longer live productively.

IV. Conclusion

1. Respondents as a whole feel the burden of being a caregiver in caring for their family members who suffer from mental disorders.
2. Characteristics of caregivers are dominated by women (62.22%), early adulthood (60%), basic education (62.22%) and low economic status (53.33%)
3. The greatest burden felt by caregivers was at a moderate level, with a total of 29 people (64.44%).

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