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# The Relationship between Stigma, Resilience, and Quality of Life from Family Members Taking Care of Schizophrenic Patients

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## ABSTRACT

Stigma in society about people with mental disorders, especially for schizophrenic patients, is very high. Stigma is not only given to schizophrenic patients but also their family members. The stigma given to family members may cause them to feel sad, ashamed, shocked, annoyed, uneasy, and blaming one another. This can affect the resilience and quality of life from family members who are taking care of schizophrenic patients. This study applied cross-sectional research in which the population was family members who accompany the schizophrenia patient to psychiatric polyclinics. The total of samples was 171 respondents who met several criteria, namely family members who were taking care of and living in the same house with the schizophrenic patients; cooperative; and be able to read and write. The variables of this study were stigma, resilience, and quality of life. Data collection was conducted using a questionnaire and analyzed using the Spearman's rho test. It showed that there was a very strong negative relationship between stigma and resilience (p = 0.000 and r = -0,851) and between stigma and quality of life (p = 0,000 and r = -0,715). Efforts to reduce stigma in society regarding schizophrenia must be carried out because stigma affects not only schizophrenic patients but also the family members who are taking care of them. The high resilience and good quality of life have positive effects on the healing process and reduce the relapse rate of schizophrenic patients.

**Keywords:** quality of life, resilience, schizophrenia, stigma

## INTRODUCTION

Schizophrenia is a severe mental disorder that affects more than 21 million people in the world [1]. The role of the family becomes very important in the treatment and recovery process of patients. Treatment for schizophrenic patients is not an easy thing for families. The process of treating the patients is often followed by the psychological burden and distress [2]. A study showed that family members taking care of schizophrenic patients dealt with psychiatric illnesses, which were different and were described as psychological stress during the treatment process [3]. The psychological stress during the treatment process can be overcome by resilience. Resilience in this context consists of the ability of families to survive and rise to determine what they should do and the ability to take care of the family who is suffering from schizophrenia [4].

A study reported that resilience in family members who were taking for schizophrenic patients had an impact on the recovery process and decreased the relapse rate for schizophrenic patients. Besides, resilience is also closely related to the quality of life. Based on a study, the family members who were taking care of schizophrenia patients had the quality of life, which decreased significantly. The decline in quality of life is due to mental, physical, and financial problems imposed on those family members. Patients' dependence on their family members is also able to eliminate the entertainment and social activities of their family

members for the sake of taking care of them [5]. Increasing the resilience of family members who are taking for schizophrenic patients is not simple things. One of the symptoms of low family resilience is the high relapse rate of schizophrenic patients. The relapse rate of schizophrenia patients in Indonesia is 50% - 80%, 57% in less than the first three years, and 70% - 82% in the first five years [6]. The high relapse rate in schizophrenic patients is one of the effects of the low resilience from family members who are taking care of them.

Stigma in society about people with mental disorders, especially for schizophrenic patients, is very high. Schizophrenic patients will experience discrimination, stereotyping, labeling, and exclusion in their lives. Stereotypes that often arise in schizophrenic patients are that they are often regarded as people who have a tendency to kill or maniac, high lust, depressed, laughing without cause, and dishonest (when meeting a doctor) [7]. Stigma is not only experienced by schizophrenic patients, but also by their family members. The stigma experienced by family members negatively impacts the healing process of schizophrenic patients because it may cause the family member to feel sad, ashamed, shocked, annoyed, uneasy, and blaming one another, which will eventually affect the quality of the healing process given to schizophrenic patients [8].

## METHODS

The type of this study was a quantitative research with a descriptive-analytic approach and cross-sectional design. This study examined the independent and dependent variables only once at the same research time and no-followed up. The applied sampling technique was the non-probability sampling method with the purposive sampling technique. The total of samples was 171 respondents who met several criteria, namely family members who were taking care of the schizophrenic outpatients, living in the

same house with schizophrenic patients, being cooperative, and being able to read and write.

The independent variable in this study was a stigma, while the dependent variable was resilience and Quality of Life (QoL) from family members who were taking care of schizophrenic patients. Data were collected using the Internalized Stigma of Mental Illness (ISMI) questionnaire to measure stigma, the 10-item Connor-Davidson Resilience Scale (10-item CD-RISC) to measure resilience, and the WHO Quality of Life-BREF (WHOQOL-BREF) to measure the quality of life. The instrument in this study had been tested for validity and reliability by previous researchers and was approved by the copyright holder of the questionnaire to be used as an instrument in this study. This study had been through ethical testing and met ethical clearance by the ethics committee of RSJ Prof. Dr. Soerojo Magelang. This study was conducted at the psychiatric polyclinic on 19 November - 2 December 2019. Furthermore, the data were analyzed using Spearman's Rho statistical test with $p \leq 0.05$. This study has implemented the ethical principle and received consent from participants.

## RESULTS

**Table 1.** General data on families caring for schizophrenia patients

| General Data | Total | Percentage |
|---|---|---|
| | n | % |
| Age | | |
| < 31 years old | 20 | 11,70 |
| 31-40 years old | 20 | 11,70 |
| 41-50 years old | 46 | 26,90 |
| 51-60 years old | 44 | 25,73 |
| > 60 years old | 41 | 23,97 |
| Total | 171 | 100 |
| Gender | | |
| Male | 82 | 47,95 |
| Female | 89 | 52,05 |
| Total | 171 | 100 |
| Profession | | |
| No job | 27 | 15,79 |
| Student/College student | 4 | 2,34 |
| Entrepreneur | 28 | 16,37 |
| Geenral employees | 22 | 12,87 |
| Civil servants | 4 | 2,34 |
| Labor | 21 | 12,28 |
| Other | 65 | 38,01 |
| Total | 171 | 100 |
| Relationship with patient | | |
| Parents | 81 | 47,37 |
| Husband/wife | 39 | 22,81 |
| Son | 16 | 9,36 |
| Brother/sister | 26 | 15,20 |
| Other | 9 | 5,26 |
| Total | 171 | 100 |
| Length of stay with the patient | | |
| < 1 year | 5 | 2,92 |
| 1-5 years | 5 | 2,92 |
| > 5 years | 161 | 94,15 |
| Total | 171 | 100 |
| Education | | |
| No education | 16 | 9,36 |
| Elementary school | 52 | 30,41 |
| Middle school | 29 | 16,96 |
| High school | 54 | 31,58 |
| College | 20 | 11,70 |
| Total | 171 | 100 |
| Income | | |
| ≤ Rp. 2.000.000 | 91 | 53,22 |
| Rp. 2.000.001-Rp. 4.000.000 | 59 | 34,50 |
| Rp. 4.000.001-Rp. 6.000.000 | 18 | 10,53 |
| Rp. 6.000.001-Rp. 8.000.000 | 1 | 0,58 |
| > Rp 8.000.000 | 2 | 1,17 |
| Total | 171 | 100 |
| Source of funds for care | | |
| Personal | 148 | 86,5 |
| Sibling | 15 | 8,8 |
| Government | 8 | 4,7 |
| Total | 171 | 100 |
| How to pay for patient care | | |
| Health insuranse | 160 | 93,57 |
| Other insurance | 1 | 0,58 |
| Personal | 10 | 5,85 |
| Total | 171 | 100 |

Table 1 above explains general data on families caring for schizophrenic patients. The age of most family members who treat patients with schizophrenia is 41-50 years old, that is 46 respondents (26.90%), the majority are female respondents 89 respondents (52.05%), work as others (farmers, retirees, coolies) as many as 65 respondents (38.01%) with the most income less than or equal to two million rupiahs, namely 91 respondents (53.22%). Most family relations are as many parents as many as 81 respondents (47.37%) with the length of stay with> 5 years which is as much as 161 respondents (94.15%). Most education of families caring for schizophrenia patients is high school with a number of 54 respondents (31.58%). Most of the sources of funds for the treatment of schizophrenic patients came from personal money as many as 148 respondents (86.5%) and payment of check fees to the clinic was by using BPJS as many as 160 respondents (93.57%).

**Table 2.** General data on schizophrenia patients

| General Data | Total | Percentage |
|---|---|---|
| | n | % |
| Age | | |
| < 21 years old | 5 | 2,92 |
| 21-30 years old | 47 | 27,49 |
| 31-40 years old | 53 | 30,99 |
| 41-50 years old | 31 | 18,13 |
| > 50 years old | 35 | 20,47 |
| Total | 171 | 100 |
| Long suffered | | |
| < 3 years | 29 | 16,96 |
| 3-5 years | 26 | 15,29 |
| > 5 years | 116 | 67,84 |
| Total | 171 | 100 |
| Last education | | |
| No. education | 7 | 4,09 |
| Elementary school | 45 | 26,32 |
| Middle school | 48 | 28,07 |
| High school | 54 | 31,58 |
| College | 17 | 9,94 |
| Total | 171 | 100 |
| Last job | | |
| No job | 77 | 45,03 |
| Student/College student | 2 | 1,17 |
| Entrepreneur | 7 | 4,09 |
| General employees | 22 | 12,87 |
| Civil servants | 2 | 1,17 |
| Labor | 18 | 10,53 |
| Other | 43 | 25,15 |

| | | |
|---|---|---|
| Total | 171 | 100 |
| | | |

Table 2 explains general data on schizophrenia patients. The most age of schizophrenia patients is 31-40 years old with 53 patients (30.99%) and the majority of patients suffering from schizophrenia are> 5 years, 116 patients (67.84%). Most of the latest schizophrenia education is high school, with 54 patients (31.58%) and the majority of schizophrenia patients who have never worked before, with 77 patients (45.03%).

Table 4 shows the level of resilience of family members caring for schizophrenia patients based on resilience parameters. Most family members who treat schizophrenia patients have high resilience which is indicated by the value of meaningfulness (purpose in life), perseverance (desire to progress), equanimity (balance), self-reliance (trust in one's abilities) and existential aloneness (independence) tall one.

Table 5 shows the quality of life of family members caring for schizophrenia patients based on the quality of life parameter. The majority of family members who care for schizophrenia patients have moderate physical health, good psychological well-being, good social relationships, and good environmental relationships.

**Table 3.** The frequency of stigma is based on the stigma parameters felt by family members caring for schizophrenic patients

| Parameter | Stigma | | | | | | | | Tota |
|---|---|---|---|---|---|---|---|---|---|
| | No | | Low | | Moderate | | High | | |
| | n | % | n | % | n | % | n | % | n |
| Alienation | 65 | 38,01 | 77 | 45,03 | 16 | 9,36 | 13 | 7,60 | 171 |
| Stereotype endorsement | 69 | 40,35 | 61 | 35,67 | 32 | 18,71 | 9 | 5,26 | 171 |
| Discrimination | 64 | 37,43 | 71 | 41,52 | 23 | 13,45 | 13 | 7,60 | 171 |
| Social withdrawal | 74 | 43,27 | 63 | 36,84 | 24 | 14,04 | 10 | 5,85 | 171 |

Table 3 explains the frequency of stigma based on the stigma parameters felt by family members caring for schizophrenic patients. The majority of family members who treat schizophrenia patients experience alienation and low discrimination and do not experience stereotype endorsement (stereotype support) and social withdrawal.

**Table 4.** Resilience level of family members caring for schizophrenia patients based on resilience parameters

| Parameter | Resilience | | | | | | Total | |
|---|---|---|---|---|---|---|---|---|
| | Low | | Moderate | | High | | | |
| | n | % | n | % | n | % | n | % |
| Meaningfulness | 11 | 6,43 | 36 | 21,05 | 124 | 72,51 | 171 | 100,00 |
| Perseverance | 9 | 5,26 | 38 | 22,22 | 124 | 72,51 | 171 | 100,00 |
| Equanimity | 8 | 4,68 | 33 | 19,30 | 130 | 76,02 | 171 | 100,00 |
| Self-reliance | 10 | 5,85 | 32 | 18,71 | 129 | 75,44 | 171 | 100,00 |
| Existential aloneness | 12 | 7,02 | 29 | 16,96 | 130 | 76,02 | 171 | 100,00 |

by p = 0.000 (p < 0.05) and r = -0.851 which meant that the lower the stigma was felt, the higher the level of resilience of family members taking care of schizophrenic patients was. Most of the family members taking care of schizophrenic patients felt a low stigma, namely 72 respondents (42.1%), and the majority of them had a high level of resilience, namely 137 respondents (77.19%).

Table 7 shows that there was a very strong negative relationship between stigma and the quality of life from family members taking care of schizophrenic patients as indicated by p =0.000 (p < 0.05) and r = -0.715 which meant that the lower the stigma was felt, the better the quality of life from family members taking care of schizophrenic patients was. Most of the family members taking care of schizophrenic patients felt a low stigma, namely 72 respondents (42.1%), and the majority of them had a good quality of life, namely 98 respondents (57.31%).

**Table 5.** Quality of life for family members who treat schizophrenia patients based on quality of life parameters

| Parameter | Quality of Life | | | | | | | | | | Total | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Very Bad | | Bad | | Moderate | | Good | | Very Good | | | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Physical health | 1 | 0,58 | 19 | 11,11 | 100 | 58,48 | 48 | 18,07 | 3 | 1,75 | 171 | 100 |
| Psychological well-being | 0 | 0 | 2 | 1,17 | 50 | 29,24 | 87 | 50,88 | 32 | 18,71 | 171 | 100 |
| Social relations | 14 | 8,19 | 12 | 7,02 | 22 | 12,87 | 92 | 53,80 | 31 | 18,13 | 171 | 100 |
| Relationship with the environment | 1 | 0,58 | 17 | 9,94 | 30 | 17,54 | 92 | 53,80 | 31 | 18,13 | 171 | 100 |

**Table 6.** Frequency of respondents in the study of the relationship between stigma and resilience of family members caring for schizophrenic patients

| Stigma | Resilience | | | | | | Total | |
|---|---|---|---|---|---|---|---|---|
| | Low | | Moderate | | High | | | |
| | n | % | n | % | n | % | n | % |
| No stigma | 0 | 0 | 0 | 0,00 | 67 | 50,76 | 67 | 39,18 |
| Low stigma | 2 | 16,7 | 7 | 25,9 | 63 | 47,7 | 72 | 42,1 |
| Moderate stigma | 3 | 25,00 | 16 | 59,26 | 2 | 1,52 | 21 | 12,28 |
| High stigma | 7 | 58,33 | 4 | 14,81 | 0 | 0 | 11 | 6,43 |
| Total | 12 | 100 | 27 | 100 | 132 | 100 | 171 | 100 |
| Spearman's rho | p = 0,000 | | r = -0,851 | | | | | |

**Table 7.** The frequency of respondents in the study of the relationship between stigma and the quality of life of family members caring for schizophrenic patients

| Stigma | Quality of Life | | | | | | | | | | Total | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Very Bad | | Bad | | Moderate | | Good | | Very Good | | | |
| | f | % | f | % | f | % | f | % | f | % | f | % |
| No stigma | 0 | 0 | 0 | 0 | 0 | 0 | 44 | 44,90 | 23 | 100 | 67 | 100 |
| Low stigma | 0 | 0 | 2 | 8,7 | 18 | 69,2 | 52 | 53,1 | 0 | 0 | 72 | 42,1 |
| Moderate stigma | 0 | 0 | 11 | 47,83 | 8 | 30,77 | 2 | 2,04 | 0 | 0 | 21 | 12,28 |
| High stigma | 1 | 100 | 10 | 43,38 | 0 | 0 | 0 | 0 | 0 | 0 | 11 | 0 |
| Total | 1 | 100 | 23 | 100 | 26 | 100 | 98 | 100 | 23 | 100 | 171 | 100 |
| Spearman's rho | p = 0,000 | | | | r = -0,715 | | | | | | | |

## DISCUSSION

Stigma is the exclusion of individuals by the society where individuals get negative words and behavior [9]. Meanwhile, the perceived stigma (internalized stigma, self-stigma, felt stigma) is a condition where individuals who get negative stigma or label begin being affected and supporting that stigma [10]. Those individuals truly believe that they deserve that negative stereotype, and consequently, they begin isolating themselves due to negative feelings, such as shame and unworthiness [11]. According to Boyd, Adler, Otilingam, & Peters, the dimensions of perceived stigma or internalized stigma consist of alienation, stereotype endorsement, discrimination, and social withdrawal [12].

The results of this study showed that the stigma felt by family members taking care of schizophrenic patients was categorized as a low stigma. The low stigma in this study was the low level of alienation, lack of stereotype endorsement, the low level of discrimination, and no social withdrawal. The first dimension of stigma is alienation. Alienation is a feeling of not being part of anything and a feeling that no one

cares about anything that happens to them [12]. The low level of alienation in this study was indicated by disagreement on several things, including feeling being in the wrong place in this world, ashamed, low self-esteem, and disappointed because of having a schizophrenic family. Family members taking care of schizophrenic patients also disagreed with the notion that having a schizophrenic family was life-damaging, and people who did not have a schizophrenic family could not understand.

The second dimension of stigma is stereotype endorsement. Stereotype endorsement is a belief to other people who put them into a category, and it is maintained through social rules and social interaction [12]. The lack of stereotype endorsement in this study was indicated by strong disagreement expressed by family members taking care of schizophrenic patients towards statements that patients tended to commit violence, should not get married, could not carry on their life properly, and could not be useful for society. Family members taking care of schizophrenic patients did not need the help of others to make important decisions for them, could contribute to society, and believed that stereotypes about schizophrenia did not bother their families.

The third dimension of stigma is discrimination. Discrimination is an unfair treatment given by society to distinguish individuals or groups based on their categories or their distinctive attributes [12]. The low level of discrimination in this study was indicated by agreement expressed by family members taking care of schizophrenic patients regarding people around who only occasionally committed discrimination, people around who showed the patronizing attitude or treat them like a child, and people around who neglected or did not care about responding those family members taking care of schizophrenic patients. However, family members taking care of schizophrenic patients did not agree with the statement that no one was interested in getting closer, or other people would think that they could not accomplish anything.

The last dimension of stigma is social withdrawal. Social withdrawal is a consistent tendency in terms of time and place to be alone, followed by the feeling of anxiety when dealing with others [12]. No social withdrawal was reported in this study. It could be indicated by strong disagreement statement towards response regarding the statement that they avoided making relationship, and they did not socialize much, they told less about their family and the negative viewpoints concerning schizophrenia that made their family isolated, they had the feeling of being in the wrong place in this world because of having a schizophrenic family. Family members taking care of schizophrenic patients also strongly disagreed with the statement that other people could find out that they had a schizophrenic family just by looking at the appearance and by withdrawing from social situations to protect family and friends from feeling ashamed.

The results showed that the resilience of family members taking care of schizophrenic patients was in a high level of resilience. This was seen from the results of the questionnaire of resilience, which indicated a high score on all dimensions of resilience, namely meaningfulness, perseverance, equanimity, self-reliance, and existential aloneness. The high resilience in this study was indicated by the high frequency of family members taking care of schizophrenic patients to adapt towards the changes, to overcome all the things that happened, to see the comedy side of their problem, to use the coping stress to strengthen themselves, to be able to rise after experiencing downfall, to keep calm even under the problem, to do not give up easily because of failure, to consider themselves as a strong person, and to be able to handle unpleasant feelings.

The relationship between the low stigma felt by family members taking care of schizophrenic patients and the high resilience of family members taking care of schizophrenic patients is caused by several factors. A study conducted by Setyowati & Retnowati revealed that family members taking care of schizophrenic patients showed resilience by conducting effective coping, willing to understand patient's weaknesses, finding meaning in life, and having positive hope for the patient [13]. The internal factor that also influenced resilience in family members taking care of schizophrenic patients was personality traits. The personality traits that could be observed directly were affectionate, actively sociable, actively sharing stories, having a willingness to learn, and working diligently. The external factor that also influenced resilience in family members taking care of schizophrenic patients was social supports from families, society, health workers, local governments, and religious communities. The family also received social support in the form of emotional support, appreciation support, information support, and instrumental support [14].

Besides internal and external factors from family, demographic factors could also influence the stigma and resilience of family members taking care of schizophrenic

patients [15]. Demographic factors that could influence the resilience of family members taking care of schizophrenic patients in this study were age, gender, family relation with the patient, length of the patient's sickness, and length of staying with patients. Besides, education also played an important role in reducing stigma and increasing resilience [16].

Besides stigma and resilience, this study also obtained results about the quality of life from family members taking care of schizophrenic patients. The quality of life was a term that showed the physical, social, and emotional health of someone and his ability to carry out daily tasks [17]. The WHOQOL-BREF stated that the quality of life consisted of four dimensions, namely physical health, psychological well-being, social relationships, and environmental relationships. The results showed that the quality of life from family members taking care of schizophrenic patients was categorized as a good quality of life. The good quality of life in this study was indicated by sufficient physical health, good psychological well-being, good social relationships, and good environmental relationships [18].

Physical health included daily activities, dependence on drugs, energy and fatigue, mobility, pain and discomfort, sleep/rest, and working capacity [18]. The sufficient physical health in this study was that family members taking care of schizophrenic patients felt a little physical pain, needed a little medical therapy to be able to continue their daily activities, had sufficient vitality for daily activities, could get along well, felt satisfied with their sleep, felt satisfied with the ability to carry out their activities, and felt satisfied with their working ability.

Psychological well-being included body image appearance, negative feelings, positive feelings, self-esteem, spiritual/religious/personal beliefs, thinking, learning, memory, and concentration [18]. The good psychological well-being in this study was that family members taking care of schizophrenic patients often enjoyed their life and felt their life meaningful, were able to concentrate, were able to accept their body appearance, felt satisfied with themselves, and rarely had negative feelings.

The social relationship included personal relationships, social support, and sexual activity [18]. The good social relationships in this study were that family members taking care of schizophrenic patients felt satisfied with personal or social relationships, satisfied with their sexual life, and satisfied with support obtained from friends.

The environmental relationship in this study included financial resources, freedom, physical security and safety, health and social care including accessibility and quality, the environment of home, the opportunity to get a variety of new information and skills, participation, the opportunity to do recreational and fun activities in leisure time, and physical environment including pollution, noise, traffic, climate, and transportation [18]. The good environmental relationships in this study were that family members taking care of schizophrenic patients felt safe in running their everyday life, had a healthy living environment, had sufficient money to fulfill the living cost, frequently had the opportunity to do recreational and fun activities, felt satisfied with access to health care services, and felt satisfied with the transportation system which supported the mobility access.

The low perceived stigma meant that the environment also supported the healing process of the patients. By not labeling schizophrenic patients with negative labels and the provision of good psychiatric services, it could also reduce the burden of the family in taking care of the patients. The small burden of the family in taking care of the patients could improve the quality of life from family members taking care of schizophrenic patients [19].

This was in line with the study conducted by Jack-ideas, Uys, & Middleton, which revealed that the provision of free psychiatric care, especially medication, could help families in reducing many difficulties experienced in maintaining the healing process of schizophrenic patients. In the same study, it also presented recommendations that could be applied to reduce stigma and to improve quality of life, including integrating mental health services into general health care and providing appropriate and effective mental health training for health workers [20]. A study conducted by Hyun explained that strategies to reduce stigma to improve quality of life included recognizing the stigma, developing coping techniques, and identifying a safe and supportive environment [21].

## CONCLUSION

Based on the results and discussion of this research on the relationship between stigma and resilience and the quality of life from family members taking care of schizophrenic patients, it can be concluded as follow: there is a relationship between the perceived stigma and resilience of family members taking care of schizophrenic patients, there is a relationship between the perceived stigma and the quality of life from family members taking care of schizophrenic patients.

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