

Differences in Depression Based on Stigma among Caregiver Female of People with Schizophrenia

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Abstract

Schizophrenia is a serious mental disorder characterized by fundamental disturbances in thinking, perception and emotions. In addition to the burden felt directly by the sufferer, the family or relatives of the person with schizophrenia also experience the same burden. This family cared for them in their home, participated in treatment and rehabilitation. The World Health Organization (WHO) reports that stigma is one of the biggest obstacles in dealing with mental disorders. Overcoming stigma is very important in reducing depression rates in families of people with schizophrenia. This study was a cross sectional study using a categorical comparative analytic design, which was conducted at RSJ Prof. dr. M. Ildrem Medan, North Sumatra from June to December 2019. The research subjects were 86 female caregivers of people with schizophrenia. The measuring instrument used to assess stigma is the Stigma Items from the Schedule for Clinical Assessment in Neuro Psychiatry (SI from SCAN) / Family Interview Scale, and depression is assessed using the Beck Depression Inventory II (BDI-II). From all research subjects, it was found that 72 subjects (83.7%) experienced severe stigma to date and 14 subjects (16.3%) experienced mild stigma in caring for family members who suffer from schizophrenia. The results of the analysis using the chi-square test obtained p value = 0.001 ($p < 0.05$). There was a very significant difference in depression based on the stigma of female caregivers of people with schizophrenia.

Keywords

caregiver female; schizophrenia; depression; stigma



I. Introduction

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 decision-making 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.

Schizophrenia is a serious mental disorder characterized by fundamental disturbances in thinking, perception and emotions. Schizophrenia is one of the most aggravating disorders worldwide. In addition to the burden felt directly by the sufferer, the family or relatives of the person with schizophrenia also experience the same burden.

Schizophrenia is a serious mental disorder affecting 7 per 1000 adult population, mostly between the ages of 15 - 35 years. According to the World Health Organization (WHO) an estimated 29 million people suffer from schizophrenia. Although the incidence rate is low (3 per 10,000), the prevalence rate is relatively high which is associated with the chronic nature of the disorder. Some studies have estimated that 20% of people with schizophrenia have persistent symptoms and have increased disability, and about 35% of

them exhibit a mixed pattern with different rates of remission and exacerbation.

Schizophrenia is a group of psychotic disorders with distortions typical of thought processes, sometimes having the feeling that they are being controlled by outside forces, sometimes delusive understandings, impaired perception, abnormal affect integrated with real or actual situations, and autism. Schizophrenia is the most frequent psychotic disorder. Nearly 1% of the world's population suffers from schizophrenia during their lifetime. Symptoms of schizophrenia usually appear in late teens or young adults. Onset in men is usually between 15-25 years and in women between 25-35 years. Prognosis is usually worse in men compared to women. Onset after age 40 is rare (Elvira in Humairah, 2013).

Stigma comes from the Greek word "stigmata", which refers to an embarrassing or cornering sign, a blot or an identifying mark or characteristic.⁵ Erving Goffman (1922 - 1982) states that stigma is a very cornering sign to weaken someone from society and as someone who is rotten or dirty, someone who is neglected. James R. Dudley defines stigma as a "stereotype" or negative views associated with a person or group of people when their behavior or characteristics are seen as different as or lower than existing social norms.

In the 19th century, the separation of the mental health care system from the mainstream of health care exacerbated the situation associated with stigma. However, stigma comes from multiple sources that work synergistically and has serious implications in a person's life, which may come from personal, family and social settings, and the nature of the disorder itself. Stigma usually arises from a lack of awareness, lack of education, lack of understanding, and the true nature and complications that arise from mental disorders, such as strange behavior and acts of violence.

The World Health Organization has identified stigma as a major cause of social discrimination and rejection, which affects self-esteem, limits social functioning, hinders success in obtaining housing and employment, and contributes to family dysfunction. Such discriminatory behavior is stronger when people are faced with a schizophrenia diagnosis, because of the typical symptoms, disruptive behaviors, and hazards associated with the disorder.

The stigma attached to mental disorders according to WHO is one of the biggest obstacles in the handling of mental disorders. Around the world, the stigma of mental illness causes tremendous suffering, and its consequences include psychological stress and morbidity, problems in relationships, restrictions in employment, and opportunities for education. People try to avoid the label of mental disorders and try to avoid being associated with mental health service centers because of the strong influence of stigma on mental disorders.

It is a big task and responsibility in caring for people with schizophrenia and most families who care for them seem unprepared to carry out these duties and responsibilities for a long time. Mixed feelings, such as shock, anger, depression, confusion, and denial often arise among the families of people with schizophrenia. Parenting is a multi-thematic concept that includes the psychological, physical, emotional, social and financial changes faced by caregivers in providing care to family members suffering from schizophrenia. Caregiver in schizophrenia involves an assumption regarding unpaid and unexpected responsibility for the sufferer. This creates a nurturing burden and possibly an unpleasant experience for most caregivers.

Overcoming stigma is very important in reducing the rate of depression in the family of people with schizophrenia. Depression is often reported by caregivers of people with schizophrenia, with a large number of caregivers experiencing depressive symptoms by 38 to 68%. Severe stress in the family creates physical and emotional stress, and causes anxiety, guilt, and depression in family members because a family member suffers from a disorder.

Research by Magana, et al. On 85 family subjects of people with schizophrenia of Latin ethnicity found that 40% of subjects experienced depression. El-Tantawy, et al. in 2010 in Saudi Arabia, which also measured the relationship between stigma and depression rates in families of people with schizophrenia, found that stigma erodes the morale of families who nurture and help care for them, and it leads the families of people with schizophrenia to depression.

II. Research Methods

This study is a cross-sectional study using a categorical comparative analysis which took place from June to December 2019 and has received approval from the Ethics Commission of the Faculty of Medicine, University of North Sumatra. This study included 86 female subjects as caregivers of people with schizophrenia with several inclusion and exclusion criteria.

The inclusion criteria are:

- Second degree family members who care for the person with schizophrenia and live in the same house with the person with schizophrenia, and interact for at least 10 hours per week for a minimum of 6 months;
 - Are female;
 - 18-60 years old;
 - Minimum primary school education.
- The exclusion criteria are:
- Caregivers of people with schizophrenia who have mental disorders.

The stigma found in study subjects was assessed using the Stigma Items of SCAN's Schedule for Clinical Assessment in Neuropsychiatry (SI) developed by Sartorius and Janca in 1996, which was developed as part of a WHO study on the course of disease and the consequences of schizophrenia. paying special attention to stigma and its attributes. This measuring instrument consists of nine dimensions, namely self-esteem (SI 2, SI 3, and SI 5), stereotype (SI 7), discrimination (SI 1 and SI 9), shame (SI 11), guilt / blame (SI 8 and SI 14), isolation (SI 10), avoidance behavior (SI 6), depression (SI 13), help (SI 4 and SI 12) . The total consisted of 14 items dealing with stigma that might affect the family of a person with schizophrenia. Each stigma item is scored on a four-point scale starting with the number 0 (not at all), number 1 (sometimes), number 2 (often), and number 3 (very often). With regard to stigma for estimating or estimating the response to the stigma distribution, the stigma count score was calculated by summarizing all positive responses greater than 0 for each of the 14 questions. The result is a score of 0 for no stigma, a score of 1 - 4 for mild stigma, and a score of > 4 for severe stigma.

SCAN's SI measuring instrument in Indonesian can measure true stigma with a sensitivity of 90% and a specificity of 98%. For internal consistency, the SI of SCAN has a Cronbach alpha value of 0.786.

Depression was assessed using a Beck Depression Inventory II (BDI-II) of 21 self-report items that had been validated into Indonesian to screen for depression in Indonesia. The reliability value of Cronbach's alpha was 0.90, with a sensitivity of 73% and a specificity of 73%. The cut-off value of the Indonesian version of BDI-II to indicate depression is 17.

Processing and statistical analysis of the data obtained were computerized using the Statistical Package for Social Science (SPSS) program, and the research data were analyzed using the chi square statistical test.

III. Result and Discussion

The research which took place at RSJ Prof. dr. M. Ildrem Medan screened 86 female caregivers research subjects from people with schizophrenia who came with people with schizophrenia to the outpatient installation of the hospital. The study subjects were divided into two groups in equal numbers based on the depression that occurred in the subject.

From table 1, shows the demographic characteristics of the research subjects, where the most age groups are at the age of 51-60 years as many as 43 subjects (50%), the most educational characteristics in high school are 37 subjects (43.1%), the most occupational characteristics are in Work status is 48 subjects (55.8%), in the characteristics of marital status the most is married status is 83 subjects (86.5%), and in the characteristics of kinship status the most is birth mother status as many as 71 subjects (82.6%).

Table 1. Demographic characteristic of research subjects

Demographic Characteristics	n	%
Age (Year)		
18 – 30	4	4,7
31 – 40	9	10,5
41 – 50	30	34,8
51 – 60	43	50
Education		
Primary School	13	15,2
Junior High School	21	24,4
Senior High School	37	43
Higher Education	15	17,4
Occupation		
Does not work	38	44,2
Work	48	55,8
Marital status		
Unmarried	3	3,5
Married	83	96,5
Kinship status (biological)		
Mother	71	82,6
Sisters	15	17,4

Table 2 shows the demographic characteristics of each group, where the characteristics based on age indicate that 4 subjects (4.7%) did not experience depression, 9 subjects (10.5%) aged 31-40 years.) do not experience depression, at the age of 41 - 50 years as many as 15 subjects (17.4%) experienced depression and 15 subjects (17.4%) were not depressed, and at the age of 51 - 60 years as many as 28 subjects (32.6%)) suffered from depression and 15 subjects (17.4%) were not depressed. In this age characteristic, there was a very significant relationship between the age of the study subject and the depression condition, which was indicated by a p value <0.001 (p <0.05).

On the educational characteristics of the subject shows that 9 subjects (10.5%) experience depression and 4 subjects (4.7%) do not experience depression, at the junior high school level (SMP) as many as 10 subjects (11.6%) experienced depression and 11 subjects (12.8%) did not experience depression, for high school education (SMA) as many as 17 subjects (19.8%) experienced depression and 20 subjects (23.2%) did not. experiencing depression, 7 subjects (8.1%) had depression and 8 subjects (9.3%) were not depressed. With a p value = 0.516 (p <0.05), it shows a non-significant relationship between education level and depression in the subject.

In the job characteristics, 21 subjects (24.4%) experienced depression and 27 subjects (31.4%) did not experience depression, and 22 subjects (25.6%) had no depression. and 16 subjects (18.6%) were not depressed. There was no significant relationship between work and depression as indicated by the value of $p = 0.278$ ($p < 0.05$).

On the characteristics of marital status, 3 subjects with unmarried status (3.5%) were not depressed, and 43 subjects (50%) experienced depression and 40 subjects (46.5%) were not depressed. The marital status characteristics showed no significant relationship with depression as indicated by the value of $p = 0.241$ ($p < 0.05$).

In the characteristics of kinship status, as many as 43 subjects (50%) experienced depression and 27 subjects (31.4%) were not depressed, 15 subjects (17.4%) did not experience depression in their kinship status as sisters. and as much as 1 subject (1.2%) in kinship status as aunt also did not experience depression. Kinship status has a very significant relationship with depression in the subject, with a p value < 0.001 ($p < 0.05$).

Table 2. Distribution of study subjects based on demographic characteristics

Demographic Characteristics	Depresi		Tidak Depresi		<i>p</i>
	n	%	n	%	
Age (Year)					
18 – 30	0	0	4	4,7	0,001**
31 – 40	0	0	9	10,5	
41 – 50	15	17,4	15	17,4	
51 – 60	28	32,6	15	17,4	
Education					
Primary School	9	10,5	4	4,7	0,516*
Junior High School	10	11,6	11	12,8	
Senior High School	17	19,8	20	23,2	
Higher Education	7	8,1	8	9,3	
Occupation					
Does not Work	22	25,6	16	18,6	0,278*
Work	21	24,4	27	31,4	
Marital Status					
Unmarried	0	0	3	3,5	0,241***
Married	43	50	40	46,5	
Kinship status (Biological)					
Mother	43	50	27	31,4	0,001**
Sister	0	0	15	17,4	
Aunty	0	0	1	1,2	

* Chi-square test

**Mann-Whitney test

***Fisher test

In table 3, no stigma is combined with mild stigma because there are no study subjects who show no stigma, both in the depression group and the no depression group. The statistical consideration was that because the observed value was small, 15 it could be combined between absent stigma and mild stigma. Table 3 shows that as many as 43 subjects (100%) in the depression group experienced severe stigma and none of the subjects in this group experienced a mild stigma or none experienced stigma in caring for their family members suffering from schizophrenia. Meanwhile, in the no depression group, 29 subjects (67.4%) had severe stigma and 14 subjects (32.6%) had mild or no stigma. From all research subjects, it was found that 72 subjects (83.7%) experienced severe stigma to date and 14 subjects (16.3%) had never experienced mild stigma or stigma in caring for family members

who suffer from schizophrenia. The results of the chi-square test showed a very significant difference between depression and stigma, as indicated by the value of $p < 0.001$ ($p < 0.05$).

Table 3. Difference between depression and stigma

Stigma	Depression				Total (%)	<i>p</i>
	There is		Nothing			
	n	%	n	%		
None / light	0	0	14	32,6	4 (16,3)	0,001
Heavy	43	100	29	67,4	2 (83,7)	
Total	43	100	43	100	5 (100)	

The overall study subjects were women, in line with estimates from the World Federation of Mental Health (WFMH) in 2010 that globally, approximately 80% of caregivers are women, possibly the mother, wife, or sister of a person with schizophrenia. As in the United Kingdom, about 58% of caregivers are women, as well as in Asian countries, where 70% of caregivers are women and women exhibit high distress in their position as caregivers.¹⁶ Women as caregivers exhibit coping mechanisms less positive about symptoms in families with schizophrenia than male caregivers, and women were more attentive and open to their feelings. However, this situation was different in the study by El-Tantawy et al. in Saudi Arabia that married male family members are accountable to people with schizophrenia, both inside and outside the home. This is related to the culture in the area which restricts women from dealing with foreigners, especially men in caring for their family members

From the demographic characteristics of the research subjects, on the age characteristics, the most research subjects were aged 51 to 60 years (50%). And at this age, compared to other ages, more than half of the study subjects experienced depression (32.6%). In Asian culture, the elderly individual in the family is the “head of the household”, who bears great responsibility for looking after family members and taking responsibility for their health. Older caregivers are faced with feelings of worry, inability, and uncertainty that they may no longer be able to fulfill their roles as they age. Middle-age and old-age women who care for families with illness or disabilities, especially their spouses, have nearly six times as many symptoms of depression and anxiety as women who do not have the responsibility of taking care of a family that does not suffer from disturbances. However, different things were found in the study of Singh, et al. which states that young caregivers exhibit high rates of depression. Likewise with research by Magana, et al. which suggests the outcome of depression in young caregivers. This occurs, particularly in those in their teens and early mid-teens, because they may have additional social responsibilities and roles, such as work and other caring roles (raising children and caring for Elderly people). On the other hand, older caregivers may have more time to develop resources and coping strategies to reduce psychological distress, and they have more life experience dealing with stressful situations.

The characteristics of the educational level of the research subjects showed that subjects in the depression group who attended high school education (19.8%) had experienced more depression compared to other levels of education. This is not in line with research by Magana, et al. which suggests that lower education levels of caregivers are associated with depression. In the context of caring for people with schizophrenia, low education may be associated with low economic status and thus fewer resources are available to caregivers.

Research subjects with work status work more than study subjects who do not work, and from that work status, more research subjects are in the group of research subjects who

are not depressed (31.4%). This may be influenced by the medical costs of people with schizophrenia which have been borne by the state through health insurance programs so that they do not become a burden for the caregivers of the person with schizophrenia. This condition is in line with research by El-Tantawy, et al. where the states helps people with schizophrenia and their families in financial aspects and cover all costs for the treatment of people with schizophrenia.

The majority of study subjects with maternal kinship status (81.4%) in this study, where for the depression group, the dominating mother (50%) showed depression compared to other kinship status. This is in line with research by Uddin, et al. which shows that mothers have a higher rate of depression than other family members who are caregivers of people with schizophrenia. In the group of parents of young patients with psychotic disorders, 2/3 of the mothers in that group are concerned about their child's disorders. In most families, women of middle age or older take on caring responsibilities and are mostly mothers. The life of the mother is shaped by the conditions of care and to meet the needs of the person with schizophrenia. Mothers with children who suffer from schizophrenia experience problems in their relationship with their sick children. In addition, the mother feels that she has lost the potential of her child to maintain a normal life and also feels that she has lost her freedom to live her own life.

This study shows that the stigma that appears in female caregivers of people with schizophrenia leads to more severe stigma, as many as 72 (83.7%) subjects. In a study conducted by Singh, et al. found that female caregivers exhibited a high level of perceived stigma. Research conducted by Yin et al. in China it shows that caregivers of people with schizophrenia experience stigma at almost all times in their daily lives, which is linked to social support, forms of kinship, sufferers' educational level, and place of residence.

IV. Conclusion

This study also showed a very significant relationship between depression and stigma ($p < 0.001$). This study is in accordance with research conducted by Magana, et al. which showed a significant association between depressive symptoms and the stigma associated with caregivers of people with schizophrenia. So was the study by El-Tantawy et al. which indicates a high level of depressive symptoms in caregivers from schizophrenia is related to the magnitude of the perceived stigma attached to caregivers.² This significant relationship between depression and stigma can be a barrier to improvement for the person with schizophrenia and erode morale from caregivers.² The stigma that appears both to sufferers and their families is responsible for the delay in seeking treatment and also treatment adherence. In addition, this condition can also have an impact on the social life of the caregiver, because it will limit the caregiver in dealing with the surrounding environment (neighbors or friends) and other families.

The drawbacks of this study were that it did not measure the time spent caring for people with schizophrenia, the severity of symptoms of people with schizophrenia, and the number of repeated treatments a person with schizophrenia has had in a mental health institution, where these factors can influence the psychological condition of female caregivers. of people with schizophrenia.

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