

ARTICLE

The fight against stigma: Multilevel stigma interventions in schizophrenia patients

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Abstract

Background: Stigma is one of the main factors causing *pasung* (physical restraint or confinement in Indonesian terms) in schizophrenia patients. It is the main obstacle to reducing the number of *pasung* throughout the world. Thus, there is a need for appropriate interventions to reduce stigma in schizophrenia patients who go through *pasung*. This study aims to identify multilevel stigma interventions in people with schizophrenia who go through *pasung* (physical restraint and confinement). It can be applied and adapted to various cultural contexts.

Design and Methods: Quasi-experimental research with pretest and post-test analysis consists of 82 people with schizophrenia who go through *pasung*. Respondents were divided into the intervention group and the control group. A multilevel stigma intervention was given to the intervention group for three months.

Results: There was a significant difference in the average stigma score in the control group (moderate category stigma) and the intervention group (mild category stigma) after multilevel stigma intervention (p -value = 0.04). The average stigma score of schizophrenia patients in the intervention group decreased by 8.2%, while the average stigma score in the control group increase of 20.4%.

Conclusions: Multilevel stigma interventions are effective in reducing stigma in people with schizophrenia who go through *pasung*. We underline that multilevel stigma interventions through collaboration from various parties can provide great opportunities in stigma reduction programs in people with schizophrenia who go through *pasung*.

Introduction

“Biarkan dia tetap diikat, dia tidak akan pernah bisa sembuh, pasti akan mengamuk. Saya lebih tenang tetap bisa melihatnya, saya malu jika nanti dia ngamuk lagi dilihatin orang banyak”

“Keep him bound, he will never be healed, will definitely go on a rampage. I am calmer if I can still see him. I’m embarrassed if he goes berserk to be seen by many people”

The previous quote is a family expression of patients with schizophrenia who experience *pasung*. *Pasung*, in Indonesian terms, refers to physical restraint or confinement of the mentally ill. Restraints or confinement (*Pasung*) is a well-known phenomenon in Indonesia and carried out by families on family members who have mental disorders or schizophrenia have been widely carried out.¹ Aggressive or violent behavior, unemployment in the family, and negative family attitudes towards patients are factors related to *pasung* actions.² Also, community factors such as discrimination and stigma play an important role in the idea of *pasung* to patients with schizophrenia.³

Schizophrenia is a chronic mental disorder that attacks 20 million people worldwide.⁴ Based on Riset Kesehatan Dasar (Basic Health Research) results,⁵ the prevalence of schizophrenia in Indonesia reaches 7 per 1000 households where 14% of the schizophrenia has experienced *pasung*. Schizophrenia is characterized as a distortion in thinking, perception, emotion, language, and behavior, including hallucinations and delusions. People with schizophrenia are 2-3 times more likely to die earlier than the general population. Besides, schizophrenia is associated with a large burden of disease and disability that affects the education and work of individuals who suffer it.^{4,6}

In almost every community, especially in developing countries, schizophrenia is closely related to stigmatization. Stigma is the negative labeling on a group of people that refers to the exclu-

Significance for public health

Schizophrenia is a chronic mental disorder that is closely related to stigmatization. Stigma and discrimination in patients with schizophrenia lead to poor medication adherence, leading to poor images and low self-esteem in patients. Also, stigma causes patients and families to be reluctant to seek medical treatment for their clinical conditions, so that stigma is closely related to the process of treating patients with schizophrenia. This study illustrates the effect of multilevel stigma interventions on decreasing stigmatization in people with schizophrenia. This study's results are expected to contribute to the provision of interventions to reduce stigmatization in schizophrenia patients throughout the scope of health care.

sion of individuals by community members. Stigma consists of two main factors, namely negative attitudes, and discrimination. In addition, stigma is then divided into three levels, namely public (*i.e.*, how stigma manifests in society, culture, and daily habits), structural (*i.e.*, at the level of organizational and employer functions), and personal (*i.e.*, how patients perceive themselves).^{7,8} Prejudice and discrimination cause patients with schizophrenia avoided by others, get negative comments and gossiping, loss of status and respect in the family, difficulty keeping jobs or education, difficulty having marriage and experience divorce and difficulty getting help for health problems,⁹ one of which includes *pasung*. Stigma and schizophrenia is a vicious circle of relationships that harms and increases the burden on patients and families.

Stigma is related to the process of treating patients with schizophrenia. Stigma causes devastating consequences in patients with mental disorders, causing patients to lose self-esteem, leading factors to adverse mental health outcomes, delays treatment-seeking, and reduces the likelihood that a mentally ill patient receives adequate care.^{10,11} Family support is one of the factors that play a role in increasing self-esteem in patients with schizophrenia. Patients with schizophrenia who experience stigma lose the opportunity to work and lose the opportunity to live independently and safely. So it is important to reduce and eliminate the stigma that appears in the community.¹²⁻¹⁵ One intervention that can reduce stigma in society is by providing multilevel stigma interventions.

Stigma is a multilevel global phenomenon that requires an intervention approach targeting various levels, such as the individual, interpersonal, community, and structural levels. The provision of multilevel stigma interventions is expected to increase efforts to reduce stigma in the community because it can be more reaching out and more holistic than a single intervention.^{16,17} Therefore, this study aims to identify multilevel stigma interventions in people with schizophrenia who go through *pasung* that can be applied and adapted to various cultural contexts.

Design and Methods

This study uses a quasi-experimental design with a pretest and post-test with control group. This study's population was patients with schizophrenia who go through *pasung* that live in three districts in East Java Province, consisting of 150 respondents. The inclusion criteria are i) at least one month's retirement, ii) mature or at least 20 years old, iii) able to communicate well using Indonesian or Javanese. The exclusion criteria in this study were patients who experienced mental retardation. The sampling used in this study is the cluster random sampling. The sample size who met the inclusion and exclusion criteria was 82 people divided into two, 41 respondents for each control and intervention group. In addition to providing interventions for patients with schizophrenia who go through *pasung*, interventions were also given to families

(n=41), community leaders (n=41), health cadres (n=20), and health workers (n=20). The sample distribution for the two groups of patients with schizophrenia who go through *pasung* in each district is described in Table 1.

This research was conducted in January until August 2019, and was carried out by applying multilevel stigma interventions in the intervention group of patients with schizophrenia and the target group (family, community leaders, health cadres, and health workers). Meanwhile, the control group was given standard intervention in the form of health education related to mental health, *pasung*, and stigma. Data analysis was performed using SPSS 16 for windows. The descriptive analysis includes the frequency distribution for demographic data in the target group. Independent *t*-test, paired *t*-test, and Wilcoxon were performed to analyze the effect of multilevel stigma interventions on stigma reduction.

This study was approved by the Health Research Ethics Commission of the Faculty of Nursing, University of Indonesia (No.26 / UN2.F12.D / HKP.02.04 / 2018). Respondents were given detailed information about this study, then asked to sign the consent form. If the respondent is unable to make informed consent, a detailed explanation and consent form is given to the main caregiver (family) who is caring for the respondent. Respondents' participation is voluntary, and the confidentiality of participant information is guaranteed. After the study was completed, the control group was given the same multilevel stigma intervention program.

Multilevel stigma intervention

Multilevel stigma interventions are interventions with multilevel approaches covering three systems, namely intrapersonal, interpersonal, and structural levels. The intrapersonal level describes the provision of interventions directed at individuals to improve strategies in dealing with people who are included in the group stigmatized or change the attitudes and behavior of people who are not stigmatized. The intrapersonal level describes interventions directed at small groups. Meanwhile, the structural level describes interventions directed at the socio-political environment, such as law and policy.¹⁸ Multilevel stigma intervention is an increase in awareness of stigma and all elements involved in releasing *pasung* in patients with schizophrenia. The targets of multilevel stigma interventions in this study were schizophrenia patients who go through *pasung*, families, community leaders, health cadres, and health workers. The intervention was given for three months and was given in the form of education, training, and focus group discussions. The multilevel stigma interventions given in this study are more fully illustrated in Table 2.

Results

Descriptive analysis results on 82 participants showed that most of the participants were female (52.4%), aged 31-40 years

Table 1. Distribution of sampling.

Districts	Total population of schizophrenia patients who experience <i>pasung</i>	Intervention group	Control group	Total sample
District 1	77	18	16	34
District 2	21	8	6	14
District 3	52	15	19	34
Total	150	41	41	82

(46.3%), junior high school education (32.9%), and not working (63.4%). The age characteristics of most participants in the intervention group (46.4%), and the control group (46.4%) were 30-40 years old. Participants in the intervention group had the characteristics of mostly female (53.6%), junior high school education (34.1%), and not working (63.4%). Meanwhile, in the control group, most of the participants were female (51.2%), junior high school education (31.7%), and not working (63.4%). More complete characteristics of schizophrenia patients can be seen in Table 3. Subsequent analysis was carried out to see the difference in average stigma scores in schizophrenia patients categorized as mild stigma with a score of 16-32, moderate stigma with a score of 33-48, and severe stigma with a score of 49-64. Results analysis of the difference in the average stigma score after giving the intervention showed that the average stigma score in the control group was 34.2195 (SD=4.37, 95% CI = 0.0893-4.569) (moderate category

stigma) with a minimum value of 27 and a maximum value of 44. While in the intervention group, the average stigma score was 31.487 (SD = 3.98, 95% CI = 0.893-4.570) (mild category stigma) with a minimum value of 23 and a maximum value of 40. The results of the independent *t*-test show that there are significant differences in the average stigma score in the control group and the intervention group after multilevel stigma intervention (*p*=0.04). The results of the independent *t*-test can be seen in Table 4.

The paired *t*-test results showed that the average stigma score of schizophrenia patients who go through *pasung* in the intervention group before the intervention was 39.463 and after the intervention was 34.219 with a mean difference of 5.243 or, in other words, decreased 8.2%. The average stigma score of schizophrenia patients who go through *pasung* in the control group before the intervention was 18.463 and after the intervention was 31.487 with a mean difference of -13.024 or, in other words, an increase of

Table 2. Multilevel stigma interventions in schizophrenia patients who experience *pasung*.

Target	1 st month			2 nd month			3 rd month		
	Forms of activity	Duration of activity	Topic	Forms of activity	Duration of activity	Topic	Forms of activity	Duration of activity	Topic
1. Schizophrenia patients who experience <i>pasung</i>	FGD (each target does not join the same activity)	Four weeks with 4 sessions. The length of time for each session is 60 min	1. Session 1: view of schizophrenia (definitions, signs, and symptoms)	Classroom Education and Training (each target does not join the same activity)	Four weeks with 4 sessions. The length of time for each session is 3 x 60 min	1. Session 1: training on schizophrenia (definition, how to recognize signs and symptoms)	Direct Education and Training for people with schizophrenia who are posted (integrated activities on all targets)	Four weeks with 4 sessions. The length of time for each session is 1 x 60 minutes.	1. Session 1: training on schizophrenia (definition, how to recognize signs and symptoms)
2. Family of schizophrenia patients who experience <i>pasung</i>			2. Session 2: view of <i>pasung</i> (definition, cause/reason)			2. Session 2: training on <i>pasung</i> (definition, how to control the cause/reasons for mounting)			2. Session 2: training on <i>pasung</i> (definition, how to control the cause/reasons for mounting)
3. Community leaders in the area there are schizophrenia patients who experience <i>pasung</i>			3. Session 3: training on efforts to overcome signs and symptoms in people with schizophrenia			3. Session 3: training on efforts to overcome signs and symptoms in people with schizophrenia			3. Session 3: training on efforts to overcome signs and symptoms in people with schizophrenia
4. Health cadres in the area there are schizophrenia patients who experience <i>pasung</i>			4. Session 4: An overview of the efforts being made to release people with schizophrenia that has been installed			4. Session 4: training on efforts to release people with schizophrenia who experience <i>pasung</i>			4. Session 4: training on efforts to release people with schizophrenia who experience <i>pasung</i>
5. Health workers in the area there are schizophrenia patients who experience <i>pasung</i>									

Table 3. Characteristics of schizophrenia patients who experience *pasung* (n=82).

Characteristics	Intervention group		Control group		Total	
	n=41	%	n=41	%	n=82	%
Age (year)						
21-30	6	14.6	6	14.6	12	14.6
31-40	19	46.4	19	46.4	38	46.3
41-50	8	19.5	10	24.4	18	22
51-60	8	19.5	6	14.6	14	17.1
Gender						
Male	19	46.4	20	48.8	39	47.6
Female	22	53.6	21	51.2	43	52.4
Education						
Primary school	11	26.8	12	29.3	23	28
Junior high school	14	34.1	13	31.7	27	32.9
Senior high school	10	24.4	10	24.4	20	24.4
College	2	4.9	1	2.4	3	3.7
No school	4	9.8	5	12.2	9	11
Occupation						
Farmer	10	24.4	11	26.8	21	25.6
Businessman	2	4.9	1	2.4	3	3.7
Not working	26	63.4	26	63.4	52	63.4
Etc.	3	7.3	3	7.3	6	7.3

20.4%. The statistical test results can be concluded that there is a significant change in stigma scores between before and after implementing multilevel stigma interventions ($p < 0.05$). Schizophrenia patients in the intervention group experienced a decrease in stigma scores, and the control group experienced an increase in stigma scores.

The results of this study also showed that there were significant differences between before and after the implementation of multilevel stigma interventions in families ($p = 0.000$), community leaders ($p = 0.000$), health cadres ($p = 0.000$), and health workers ($p = 0.000$). The results of statistical tests on families and community leaders indicated an increase in scores of 46.390 and 37.660, respectively, which means there was a significant decrease in stigma. All respondents had an increase in scores between before and after the intervention for health cadres and health workers. The results of a more complete paired t -test and Wilcoxon analysis can be seen in Tables 5 and 6.

Discussion

The results of this study indicate that before the intervention, the average score in the intervention group was in the moderate stigma category. It showed that the stigma in patients with schizophrenia who go through *pasung* was still quite high. The results also showed that the majority of patients with schizophrenia were unemployed and had a junior high school education. The current study results are consistent with the study of Çapar and Kavak,¹⁹ which states that most schizophrenia patients have graduated from high school (have a low level of education) and are not working.

The same study also explained that functional recovery in patients with schizophrenia associated with stigma. There is a negative and significant correlation between functional recovery such as social functionality, health and care, activities of daily life with stigma, where functional recovery of patients with schizophrenia decreases when stigma increases.

The current study results indicate that there is a significant change in stigma scores between before and after the implementation of multilevel stigma interventions in schizophrenia patients who were placed in the intervention group and the control group. The intervention group's average stigma score decreased by 8.2%, while the average stigma in the control group increased by 20.4%. Although both were significant, the intervention group experienced a decrease in stigma scores, while the control group experienced increased stigma scores. So it can be concluded that the provision of multilevel stigma interventions effectively reduces stigma scores in schizophrenia patients who experience *pasung*. Also, families, community leaders, health cadres, and health workers showed significant differences in the average stigma score after the intervention was given. This result indicated that the provision of multilevel stigma interventions could reduce stigma not only in schizophrenia patients but in people around the patient (family, community leaders, health cadres, and health workers).

The results of this study are in line with the research of Cook *et al.*,¹⁸ which explains that multilevel interventions consisting of interpersonal, intrapersonal, and structural interventions can reduce the impact of stigma throughout the system level. In addition, the application of interventions at one level can impact the failure of change at another level. Individuals in their daily lives are always associated with other systems, so that multilevel stigma

Table 4. Analysis of average stigma scores after getting multilevel stigma interventions in the control and intervention groups.

Variable	Group	n	Mean	SD	SE	Min. Max	95% CI	p-value
Stigma after intervention	Control	41	34.219	4.373	0.683	27 44	0.893-4.569	0.04
	Intervention	41	31.487	3.981	0.621	23 40	0.893-4.570	

Table 5. Differences in stigma score before and after getting interventions (paired t -test).

Group		Mean (pre-test)	Mean (post-test)	Mean (difference)	p
Schizophrenia patients	Intervention	39.463	34.219	5.243	0.01
	Control	18.463	31.487	-13.024	0.001
Families		42.512	88.902	46.390	0.000
Community leader		48.658	86.319	37.660	0.000

Table 6. Differences in stigma score before and after getting interventions (Wilcoxon test).

Group		Mean (min-max)	Negative ranks	Positive ranks	Ties	p
Health cadres	Pre-test	57.72 (30-70)	0	20	0	0.000
	Post-test	91.25 (75-100)				
Health workers	Pre-test	62.25 (27.5-75)	0	20	0	0.000
	Post-test	92.75 (75-100)				

interventions given to the three individual systems are more likely to produce long-term effects.^{20,21} So with the implementation of multilevel stigma interventions in patients with schizophrenia, in addition to reducing stigma at this time, it is also expected to reduce stigma against patients with schizophrenia in the long term.

Discriminatory, labeling, and stereotyping can be prevented by providing the correct information about mental health.²² Research shows that better knowledge about mental health that is owned is associated with low public stigma in people with mental disorders.²³ Low mental health literacy has an impact on oneself and others, for example, not being ready to decide exactly what to do when feeling symptoms related to mental health problems and resistance to interacting with mental health patients. Individuals who have learned about mental health knowledge tend to have positive attitudes toward people with mental disorders.²⁴

Stigmatization is a negative and chronic interaction between the environment often faced by most people with schizophrenia. Public stigma, self-stigma, and avoidance labels are various types of stigma, each of which has a detrimental impact on patients with schizophrenia.²⁵ Community empowerment and public empathy are social capital able to reduce stigma in patients with schizophrenia.²⁶ Family and community resilience needs to be built so that the stigma against patients with schizophrenia must be eliminated.²⁷ Thus the stigma can be controlled and does not cause a wrong understanding related to mental health. Decreasing stigma can reduce people's attitudes towards *pasung* in schizophrenia patients. Savings against people with mental disorders occur not alone but are caused by complex things, including those related to the stigma of people with mental disorders.²⁸ Serious barriers to adequate treatment in the treatment of schizophrenia are also caused by the stigma of the patient, causing a delay in initial treatment for the patient.²⁹ This condition causes schizophrenia patients to get worse and can disrupt and endanger themselves and the surrounding environment. The attitudes of resigned families of people with mental disorders allow people with mental disorders to go through *pasung*. So that families can be more able to supervise patients and not to hurt themselves and others. Besides the shame that is borne by the family, there is a stigma made by the family against family members suffering from mental disorders. So that help from the surrounding environment to treat sufferers is not needed anymore. Such shame causes the families of people with mental disorders to close themselves off from the environment.³⁰ Management of stigma in patients with schizophrenia plays a major role in health care and retention measures in patients with schizophrenia.

Conclusion

Social, interpersonal stigma and discrimination in patients with schizophrenia contribute to health disparities. Multilevel stigma interventions have been shown to reduce stigma in patients with schizophrenia who go through *pasung* (physical restraint and confinement). Collaboration from various sectors is needed to reduce stigma in patients with schizophrenia through multilevel stigma interventions. Health workers need to collaborate with policy-makers to implement these multilevel stigma interventions in all areas of health care, including structural (community and political figures). It can reduce stigma in schizophrenia patients more broadly and, in the end, can prevent retention measures in patients with schizophrenia.

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Contributions: AB, HDW, conceived of the presented idea, developed the theory and concept, and carried out the research; NALA, ADS, drafted, wrote, and revised the manuscript with support from all authors; BAK, RII, verified the method and design of the study, and supervised the finding of this work; SKI performed the statistical analysis and interpretation of data. All authors discussed the results and contributed to the final manuscript. All authors have read and approved the final version of the manuscript and agreed to be accountable for all aspects of the work.

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