The Relationship between Knowledge and Attitudes with Stigma to People with Schizophrenia (PWS)

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Abstract

Stigma contributes to low treatment compliance in people with schizophrenia (PWS). Community surveys (N=180 PWS neighbors) of the Lentera Health Nusantara Foundation were used to analyze the relationship between knowledge of and attitudes toward the PWS stigma from March to December 2020 in the Sidoarjo and Ponorogo Regencies in East Java Indonesia. This cross-sectional study using questionnaires focused on knowledge related to symptoms, causes, and treatment as well as attitudes that describe the stigma toward PWS. The study revealed that only half of the respondents from Ponorogo (57.8% and 58.9%) and Sidoarjo (58.9% and 58.9%) had relatively good knowledge and attitudes, which shows that there is still a stigma toward PWS in the community. Furthermore, respondents in Sidoarjo were 0.019 times (98.1% lower) more likely to have a negative attitude (stigma) toward PWS than respondents in Ponorogo. There is a need for a sustainable and comprehensive strategy involving stakeholders, including health facilities, governments, and communities, especially those in rural areas, to overcome this problem of increasing compliance with PWS treatment and ensuring that the condition of the PWS is stable.

Keywords: *schizophrenia, stigma, knowledge, community, treatment adherence*

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Introduction

Mental health problems, including anxiety, depression, and schizophrenia, are burdens on the world, including Indonesia. According to reports from the World Health Organization (WHO), approximately 24 million people are diagnosed with schizophrenia worldwide. According to Basic Health Research (Riskesdas) in 2018, the prevalence of households with household members (ART) with mental disorders, schizophrenia/psychosus, was 6.7/00 (permil) and was greater than that of

2013 Riskesdas, namely, 1.7 per mil (Infodatin, 2018; Kesehatan, 2019; RI, 2013). Schizophrenia is a complex chronic mental health disorder characterized by delusions, hallucinations, disorganized speech or behavior, and impaired cognitive abilities. Disability can affect personal, family, social, educational and work life (Krishna et al., 2014; S. S et al., 2015). Therefore, PWS requires regular treatment throughout life, but this is one of the greatest challenges. According to the WHO (2022), 50% of mental hospital patients have a PWS, and only 31.3% receive specialist mental health care. Nonadherence to treatment in individuals with PWS is difficult to detect; almost half of them use medication doses of less than 70%, while other articles state that treatment compliance in individuals with PWS is between 37% and 74% (Goff et al., 2010; Krishna et al., 2014). Compliance with PWS treatment in Indonesia is 51.1% (PK, 2018).

Low adherence to treatment in individuals with PWS is related to nonmedical factors, including lack of knowledge, beliefs, culture, lack of independence, and stigma (Goff et al., 2010; Krishna et al., 2014). The WHO states that one of the facts related to PWS is stigma, discrimination and even violations of human rights (HAM). Herdiyanto et al. (2017) concluded that the stigma experienced by individuals with PWSs influenced the medical treatment they received. The lower the stigma is, the greater the treatment (Herdiyanto et al., 2017). Data from Riskesdas (2018) also indicate that in Indonesia, 84.9% of PWSs undergo treatment, but only 51.1% undergo treatment regularly (PK, 2018). A lack of knowledge, perceptions, beliefs and individual characteristics such as age, gender, education and employment are factors related to stigmatizing and discriminatory attitudes (Ardiyani & Muljohardjono, 2020; Herdiyanto et al., 2017; Mardiah et al., 2020).

In the field of mental health services, "stigma" is defined as loss of status and discrimination triggered by negative stereotypes against people who are labeled as suffering from mental disorders (Link & Phelan, 2001). Stigma can be external (community stigma) or internal (self-inflicted and invisible). Community stigma is a societal belief or attitude, view, and reflection of behavior in a negative context toward someone/something that can cause people with mental disorders to be less equal and part of an inferior group (Saad et al., 2022). Community stigma toward schizophrenia sufferers, such as noncompliance with treatment, slow healing, and self-isolation from the

community environment, has a negative impact on schizophrenia sufferers (Subu et al., 2016).

Community stigma consists of several dimensions: authoritarianism, benevolence, social restrictions, and ideological measures of societal mental health (Taylor & Dear, 1981). Community stigma against PWS by isolating and giving negative labels will have a negative impact on individuals' perceptions of themselves and their future. The view of schizophrenia as a brain disease with negative impacts will increase discrimination and stigma and cause the PWS to internalize negative expectations. Therefore, the specific impact related to the community's understanding of schizophrenia should not be ignored (Sullivan et al., 2015).

The negative consequences of perceived/experienced stigma in several studies include a lack of self-esteem, poor quality of life, empowerment, seeking and complying with mental health care, and suicidality, even after symptom levels are controlled. Stigma also has a detrimental impact on employment, income, and people's views on the allocation of social benefits and health care costs. Therefore, addressing the knowledge gap about stigmatization and its causes is needed to successfully fight discrimination and promote diversity (Valery & Prouteau, 2020). Quantitative research by Zulfiana & Sulfian (2023) regarding the relationship between family support and family stigma and treatment compliance in mental disorder patients at the Central Sulawesi Provincial Regional Hospital showed that stigma (p value ≤ 0.05) is related to treatment compliance in mental disorder patients (Zulfiana & Sulfian, 2023).

In 2014, the President of the Republic of Indonesia issued Law Number 18 of 2014 concerning mental health and emphasized the right of PWSs to receive treatment in affordable and standard health services and prohibited shackling (Undang-Undang RI, 2014). However, based on Riskesdas (2018), the proportion of households with household members with mental disorders related to schizophrenia who have been confined is 14%, which is not much different from the results of Riskesdas 2013 (14.3%) (PK, 2018; RI, 2013). According to Riskesdas 2018, the prevalence rate of PWS in East Java Province is less than the national prevalence, namely, 6.4 per mile (PK, 2018). Moreover, the Ponorogo and Sidoardjo districts are among the five districts with the highest

number of PWSs with serious disorders in East Java, amounting to 2,679 in the Ponorogo district and 3,214 in the Sidoardjo district (Timur, 2021).

Currently, there is no specific research examining the stigma toward individuals with schizophrenia, especially in Indonesia (Zulfiana & Sulfian, 2023; Timur, 2021). This is what underpins the need for conducting research to address the existing knowledge gap. Research on stigma toward individuals with schizophrenia in Indonesia is certainly an important step toward filling this knowledge void. Schizophrenia is a serious mental disorder but is still often associated with stigma and negative stereotypes in the community.

In the context of Indonesia, where culture, religion, and tradition can play crucial roles in perceptions of mental disorders, such research can provide valuable insights. Through this research, we can understand how stigma is formed, what factors influence it, and how it impacts individuals living with schizophrenia. The objective of this research is primarily analytical, with the research outcomes intended to inform interventions designed to address knowledge gaps. This study also examined variations in stigma between the Ponorogo and Siduarjo regions in rural and urban contexts. Consequently, researchers have conducted fieldwork to directly engage respondents and gather responses to research inquiries.

Method

Participants

The community survey was carried out with 180 pw neighbors representing 472,714 residents in 6 subdistricts and 112 villages in the Ponorogo and Sidoarjo districts. The inclusion criteria for community members were that they were registered with a family card and were at least 18 years old and willing to be respondents. Sampling was carried out using a two-stage cluster sampling method.

Measurement

This research used a survey questionnaire that was tested for reliability and validity on respondents

who were similar to the research sample. This survey questionnaire focused on determining the level of community knowledge regarding schizophrenia issues, attitudes about causes and treatment, and the relationship with the community's views regarding stigma toward PWS. The Cronbach's alpha coefficient of the questionnaire used is 0.897.

Data Analysis

Data processing was carried out using statistical tests to determine the relationships between individual characteristics related to gender, age, education, employment, income, place of residence, and knowledge and attitudes related to stigma, with a confidence level of 95% (Infodatin, 2018; Kesehatan, 2019; RI, 2013). This research ethics review was carried out by the Ethics Committee of the Faculty of Public Health, University of Indonesia, and the study was approved with the following letter number: Ket-/UN2.F10.DII/PPM.00.02/2020.

Results

Before presenting the hypothesis test results, the researcher examined the demographic data of the study participants. Table 1 below shows the identities of respondents from Ponorogo and Sidoarjo.

Based on 180 research samples, 90 respondents were from Ponorogo, and 90 respondents were from Sidoarjo. In the Ponorogo area, the sample was dominated by women (57.8%), as was the sample in the Sidoarjo area (51.1%). The respondents in Ponorogo were mostly aged 18-55 years (56.7%) or of productive age; likewise, the respondents in Sidoarjo were more likely to be aged 18-55 years (76.7%) or of productive age. In both the Ponorogo (65.6%) and Sidoarjo (56.7%) areas, the majority of the research respondents had low education levels. Furthermore, more respondents in the Ponorogo area work informally (26.7%), while more respondents from Sidoarjo do not work (37.8%). The income of respondents in the Ponorogo area is classified as low (86.7%) or below the East Java UMR, while respondents in the Sidoarjo area have a relatively high income (61.1%) or above the East Java UMR. Knowledge about schizophrenia possessed by respondents from Ponorogo (57.8%) and Sidoarjo (58.9%) was classified as good. In addition, more than half of the respondents did not experience stigma toward PWS, both in Ponorogo (58.9%) and Sidoarjo

(58.9%) (see Table 1).

Table 1
Respondent Identity

Variable	Ponorogo		Sidoarjo	
	f	%	f	%
Gender				
Woman	52	57,8	46	51,1
Man	38	42,2	44	48,9
Age				
18-55 years old	51	56,7	69	76,7
>55 years	39	43,3	21	23,3
Education				
High	31	34,4	39	43,3
Low	59	65,6	51	56,7
Occupation				
Formal	16	17,8	24	26,7
Informal	50	55,6	32	35,6
Does not work	24	26,7	34	37,8
Income				
High	12	13,3	55	61,1
Low	78	86,7	35	38,9
Knowledge				
Good	52	57,8	53	58,9
Bad	38	42,2	37	41,1
Stigma				
No	53	58,9	53	58,9
Yes	37	41,1	37	41,1
N	90	100	90	100

However, the results of open questions regarding respondents' views on PWS showed that respondents from Ponorogo mostly thought that people in Ponorogo considered PWS scary (50 people), as did respondents from Siduarjo (43 people). Moreover, most of the respondents from Ponorogo believed that the PWS should be pitied (37 people), while most of the respondents from Siduarjo believed that the PWS was scary (38 people).

Table 2
Descriptive Analysis of Community Stigma toward PWS

Variabel	Ponorogo		Siduarjo	
	mean	*note*	*mean*	*note*
Do not understand when talking to them	2.82	agree	3.01	agree
Avoid them	2.63	agree	2.54	agree
Feeling unsafe when around them	2.70	agree	2.70	agree
Happy to invite them to come home	1.92	disagree	1.70	disagree
Feel comfortable talking to them	2.13	disagree	2.01	disagree
Do not be afraid of them	2.42	disagree	2.57	agree
Can also experience/become PWS	1.79	disagree	1.80	disagree
It is less or below normal people	1.98	disagree	2.22	disagree
Need to be pitied	2.77	agree	2.83	agree
Does not mean failure in life	3.00	agree	3.28	agree
Must always be controlled	2.43	disagree	2.72	agree
Not allowed to have children	3.02	agree	3.23	agree
Must be forced to be treated	2.36	disagree	2.28	disagree
They should be free to make decisions for themselves	3.00	agree	3.41	agree
They should be allowed to live as they wish	2.02	disagree	2.13	disagree
Their actions were unpredictable	2.09	disagree	2.27	disagree
Their behavior can be predicted like a healthy person	2.96	agree	2.98	agree

Based on the descriptive table 2 above, the average stigma response of respondents toward PWS was determined. The distribution in the table above is based on respondents' answers regarding "agree or disagree" regarding their perspectives and attitudes toward PWS. Based on the table, the

researcher highlighted 3 main focuses of the research. Respondents from Ponorogo (3.00) agreed that PWS does not mean failure in life even though they were PWS sufferers, as did respondents from Siduarjo (3.28). Respondents from Ponorogo (3.02) agreed that PWSs are not allowed to have children, as are respondents from Siduarjo (3.23). Respondents from Ponorogo (2.36) disagreed that PWS must be forced to be treated, as did respondents from Siduarjo (2.28).

Table 3
Bivariate Analysis

Variable	Stigma toward PWS				*P value*	PR	95%CI
	No		Yes				
	f	%	f	%			
Gender							
Woman	48	48,98	50	51,02	1		
Man	46	56,10	36	43,90	0,492	0,86	0,56-1,32
Age							
18-55 years old	65	54,17	55	45,83	1		
>55 years	29	48,33	31	51,67	0,53	1,13	0,72-1,75
Education							
High	34	48,57	36	51,43	1		
Low	60	54,55	50	45,45	0,572	0,88	0,57-1,36
Occupation							
Formal	27	67,50	13	32,50	1		
Informal	40	48,78	42	51,22	0,152	1,57	0,85-2,93
Does not work	27	46,55	31	53,45	0,132	1,64	0,86-3,14
Income							
High	43	64,18	24	35,82	1		
Low	51	45,13	62	54,87	0,076	1,53	0,96-2,45
Residence							
Ponorogo	36	40,00	54	60,00		1	
Sidoarjo	58	64,44	32	35,56	0,019	0,59	0,38-0,91
Knowledge							

Variable	Stigma toward PWS				*P value*	PR	95%CI
	No		Yes				
	f	%	f	%			
Good	60	60,00	40	40,00	1		
Bad	34	42,50	46	57,50	0,093	1,43	0,94-2,19

Table 3 revealed that there was no significant relationship between gender, age, education, employment, income or knowledge of community stigma toward PWS (*p value > 0,05)*. However, compared to respondents in Ponorogo, respondents in Sidoarjo had a 0.019-fold greater risk (98.1% lower) of having a poor attitude or stigma toward PWS, with a 95% CI (0.90-0.97).

Discussion

The results showed that there was no significant relationship between sex or age and the stigma of PWSs in the community. This finding is in accordance with research by Putri & Tania (2021), who reported that there was no significant relationship between gender or age and community stigma among people with schizophrenia during the COVID-19 pandemic in Pontianak (Putri & Tania, 2021). Yuan et al. (2016) reported that stigma tends to be low in adults aged between 18 and 40 years and females. This shows that young adults are more tolerant and less accepting of stigma. This may be due to increasing public knowledge about mental illness and the development of information technology (Yuan et al., 2016).

Even though the people in Ponorogo and Sidoarjo have relatively low education levels (high school or below), the research results show that there is no significant relationship between education and the stigma that the community places on PWSs. In mental health research by Yuan et al. (2016), it was found that lower education was associated with more negative attitudes toward mental illness. This shows that individuals with higher education levels have greater knowledge of mental illness. Another explanation may be that highly educated people have more access to health information or that they have a better understanding of that information because of their higher education (Yuan et al., 2016).

There are differences in occupations between people in Ponorogo who have informal workers and those in Sidoarjo who do not have jobs; however, the research results show that there is no significant relationship between work and the stigma that the community places on PWSs. Research from Putri & Tania (2021) also revealed that there is no correlation between work and stigma (Putri & Tania, 2021). However, previous research has been conducted in Japan regarding mental health professionals, whose practice in the work environment can help reduce the stigma of people with schizophrenia (Kato et al., 2021).

Regarding income, it was found that respondents in Ponorogo had incomes that were quite high or exceeded the UMR for East Java, while those in Sidoarjo had quite low incomes. However, the research results show that there is no significant relationship between income and the stigma that communities place on individuals with PWS. This finding is in line with research from Yuan et al. (2016), who found no correlation between stigma and individual income (Yuan et al., 2016). However, another mental health study explained that having a monthly income of less than SGD 2,000 predicts more prejudice and misunderstanding that can lead to stigma (Picco et al., 2016).

The use of the term "schizophrenia" is less well known among the community. The terms that are widely used for people with schizophrenia are *wong edan, gendheng, orang stress* or *orang gila,* which are translated to crazy people. The research explained that some respondents in the Ponorogo area thought that PWS were referred to as orang gila (70%), while in the Siduarjo area, respondents generally referred to them as gendheng (68,89%). The stigma question also showed that respondents from Ponorogo did not agree that they were afraid of PWS, while respondents from Siduarjo agreed that they were not afraid of PWS. Furthermore, Sidoarjo, as a rural area, has easier access to information than do urban residents in Ponorogo, which can change community stigma toward PWS. Although there are still views of individual respondents from Siduarjo, most of them think that the PWS is scary.

No significant relationship was found between the knowledge variable and stigma toward PWS. This

is possibly because in the research, there were elderly people who might influence the respondents' knowledge of the research results. Knowledge is human self-awareness obtained through life processes based on teaching and learning processes, which are influenced by the level of education and public information from various media, which have an impact on reactions and decision-making regarding a problem (Ahmadi, 2013).

Anipah et al. (2023) reported that the correlation coefficient for community stigma with the quality of life of patients with schizophrenia was -0.196. This means that the weaker the community stigma is, the greater the quality of life of patients with schizophrenia (Anipah et al., 2023). Regardless of how small the stigma is, it can affect the size of the PWS. Therefore, even though there is no significance, increasing knowledge must still be done as a way to reduce stigma.

A potential way to eliminate the existing stigma is to provide counseling or education about stigma, which is considered a strategy with a very limited success rate and even the emergence of undesirable events and negative consequences (Putri & Tania, 2021). There needs to be a sustainable and comprehensive strategy that involves stakeholders, including health facilities providing knowledge and understanding to the community regarding schizophrenia, the government providing facilities and access to community information services regarding schizophrenia, and the community utilizing information and health facilities as well as organizations or activities regarding mental health, especially those in rural areas, to overcome this problem, improve compliance with PWS treatment, and ensure that PWS conditions are stable.

There are several limitations in this research. First, the cross-sectional design used in this study prevents us from drawing conclusions about causal relationships. Furthermore, some respondents were classified as elderly, and respondents who understood Javanese better and did not easily provide an understanding of the terms used, so there were concerns that they did not understand the research objectives.

Conclusion

There was no significant relationship between gender, age, education, employment, income or knowledge of public stigma toward PWS (*p value > 0,05)*. However, only half of the respondents from Ponorogo (57.8% and 58.9%) and Sidoarjo (58.9% and 58.9%) had relatively good knowledge and attitudes, which shows that there is still a stigma toward PWS in the community. Furthermore, respondents in Sidoarjo were 0.019 times (98.1% lower) more likely to have a negative attitude (stigma) toward PWS than respondents in Ponorogo. There is a need for a sustainable and comprehensive strategy involving stakeholders, including health facilities, governments, and communities, especially those in rural areas, to overcome this problem, increase compliance with PWS treatment, and ensure that the condition of the PWS is stable.

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