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## Review

# Perceived of Survivors, Families, and Health Professionals on the Recovery Process of Schizophrenia in Indonesia: A Scoping Review

Efri Widiani<sup>1,\*</sup>, Nur Oktavia Hidayati<sup>1</sup>, Imas Rafiyah<sup>1</sup>, Indra Kusumah<sup>2</sup>

<sup>1</sup> Department of Mental Health Nursing, Faculty of Nursing, Universitas Padjadjaran, Bandung, Indonesia.

<sup>2</sup> Faculty of Psychology, Universitas Mercu Buana, Jakarta, Indonesia.

\*Corresponding author's email: [efri.widiani@unpad.ac.id](mailto:efri.widiani@unpad.ac.id)

DOI: [10.35898/ghmj-62975](https://doi.org/10.35898/ghmj-62975)

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## ABSTRACT

**Background:** The recovery process of people with Schizophrenia in Indonesia is still not optimal. The lack of success in the recovery process is indicated by the relapse rate in people with schizophrenia, which is still high.

**Aims:** This literature review aims to describe the views of ODS, families, and health workers in the ODS recovery process in Indonesia.

**Methods:** A literature search was carried out using Google Scholar and also The databases PubMed and CINAHL with the keywords Schizophrenia OR psychosis AND family OR Caregiver OR relatives OR care OR spouse OR sibling OR parents AND psychiatrist AND mental health nurse AND mental health professionals AND Perspective OR Perceived AND Recovery AND Indonesia with free-full text criteria in English and Indonesian, and publication time has no limitations.

**Results:** Based on a literature review of 13 articles, different views were obtained between survivors, families, and mental health professionals.

**Conclusion:** The results of these findings recommend that mental health policymakers consider the views of survivors, families, and health workers regarding recovery in survivors to produce appropriate strategies to help survivors achieve a state of recovery.

**Keywords:** *Perceptions; Recovery process; Schizophrenia; Survivors; Indonesia.*

**Received:** 21 November 2023, **Revised:** 21 December 2023, **Accepted:** 25 December 2023.

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## 1. Introduction

Mental disorders are syndromes of individual behavioral patterns related to distress or impairment in one or more critical human functions, including psychological, behavioral, and biological functions, and these disorders have an impact on social life (Yusuf et al., 2015). Symptoms that appear in mental disorders can include hallucinations, illusions, delusions, disturbances in thought processes thinking abilities, and abnormal behavior such as aggressiveness or catatonia. Mental disorders can become

severe, known as schizophrenia (Horan & Green, 2019). Schizophrenia is a psychotic disorder characterized by significant thoughts, emotions, and behavior disturbances. Schizophrenia is a major psychiatric disorder characterized by changes in a person's perceptions, thoughts, affects, and behavior (Sari & Subandi, 2021; Astuti et al., 2020).

Based on the World Mental Health Report (2016), the number of people with Schizophrenia worldwide has reached 24 million people or around 1 in 200 adults (aged 20 years and over). Meanwhile, in Indonesia, cases of Schizophrenia increase every year. Based on Riskesdas 2018, the prevalence of households with ART for the mental disorder Schizophrenia or psychosis is 6.7 per mile, which means there are 6-7 households with ART for the mental disorder Schizophrenia or psychosis per 1000 households. This figure has increased more than three times compared to the 2013 Riskesdas results, which were 1.7 per 1,000 households (Kementerian Kesehatan RI, 2019).

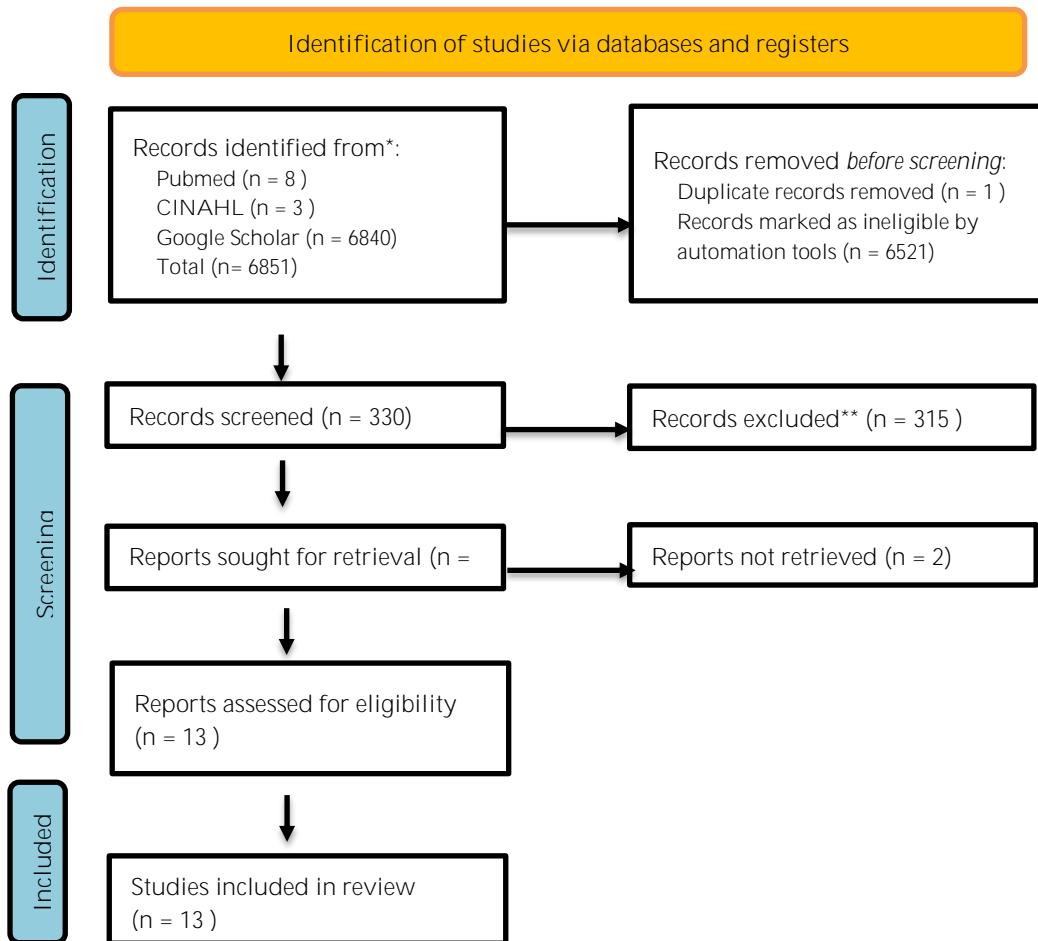
Schizophrenia impacts behavior and conditions that disturb the patient, other people, and the environment (Kurniawan et al., 2021). Schizophrenia is a complex mental health condition that can be effectively treated with somatic therapy. Somatic therapy includes antipsychotic medication, psychosocial therapy, and hospitalization when necessary. With the right treatment, individuals living with schizophrenia can experience significant improvements in their symptoms and quality of life (Asher et al., 2017). Other research states that the family can carry out medical and non-medical treatment (Suryani, Hidayah, et al., 2019). Other research shows that schizophrenic patients are taken to "dukun" to obtain an explanation of the causes of the illness and also ways to overcome it (Bachtiar et al., 2020).

The recovery process for schizophrenia survivors requires a collaborative role between various parties, including family and mental health professionals (Hidayah et al., 2022). The debate about the recovery process for schizophrenia survivors is still developing. The recovery process is defined as how individuals with mental health challenges regain and develop significant relationships with their family, friends, community, and themselves to overcome the harmful effects of stigma (Apostolopoulou et al., 2020). However, Riskesdas's (2013) data shows that as many as 1,655 households with schizophrenia still use shackling methods, which means that the stigma is still strong in society. Other research shows that shackling of schizophrenic patients is carried out due to ignorance on the part of the family, shame on the part of the family, mental disorders that do not heal, there is no cost for treatment, and the purpose of shackling is to protect ODGJ so that acts of violence do not occur (Puspitosari et al., 2019). Based on the background above, researchers are interested in conducting a scoping review regarding the picture of recovery in people with schizophrenia in Indonesia based on the views of the survivors, their families, and mental health professionals.

## 2. Methods

This review uses a scoping review approach design. A scoping review aims to identify and map existing research literature (Munn et al., 2018). The author has searched for relevant articles regarding the recovery of schizophrenia patients in Indonesia. During the process, the author used several keywords, namely Schizophrenia OR psychosis AND family OR Caregiver OR relatives OR carer OR spouse OR sibling OR parents AND psychiatrist AND mental health nurse AND mental health professionals AND Perspective OR Perceived AND Recovery AND Indonesia. The search used two electronic databases, PubMed and CINAHL, and one search engine, Google Scholar. Inclusion criteria for this study include free-text articles in English and Indonesian, excluding articles in the form of literature reviews, people diagnosed with schizophrenia, publication time has no restrictions, and articles discussing how schizophrenia patients recover in Indonesia.

Figure 1. PRISMA Flow Chart



The selection process uses PRISMA Flow Diagram 2020 according to the guidelines. The search results are in a diagram in Figure 1, which depicts the article selection process based on keywords, titles, content, and inclusion criteria for research articles. Apart from that, the selection was based on whether there was duplication or not in the literature found, resulting in 13 articles that met the requirements. Data was manually extracted from selected papers and organized in a table with columns for author and publication year following its number of sample, research methods, and results.

### 3. Results

Thirteen articles were found based on the selection criteria to explore the perceptions of schizophrenia survivors, their families, and health professionals in Indonesia about the recovery process. Out of the 13 articles, six discussed the experiences of schizophrenia survivors regarding their recovery process, seven explained the views of their families about the recovery process, and three discussed the opinions of mental health professionals on it. The details of the literature search for schizophrenia recovery can be seen in the table below:

Table 1. Results of scoping review to the perceptions of schizophrenia survivors, their families, and health professionals in Indonesia about the recovery process

<b>Health Provider: Psychiatric nurse, Mental health nurse, and Healthcare professionals</b>				
Halimah Wenny Yulina Astuti, Murti Agustin, Sri Padma Sari, Diyan Yyuli Wijayanti, Widodo Sarjana, Rozzana C. Locsin (2020)	This study aims to investigate the impact of mindfulness on hope and recovery in individuals diagnosed with schizophrenia.	Quasi-experimental	54 patients diagnosed with schizophrenia at an Indonesian mental hospital	There is a significant difference in expectations and recovery rates between the two groups, with a p-value of less than 0.001. This study indicates that mindfulness is an effective strategy.
Fandro Armando Tasigawa, Suryani, Titin Sutini, dan Sintia Rosanti Maelissa (2021)	Mental health nurses' perspectives on recovery from schizophrenia will be explored.	Phenomenology study	Eight mental health nurse	<p>After conducting the research, we identified five main themes that emerged, which include:</p> <ul style="list-style-type: none"> <li>• Treating patients with a personal touch, as if they were family members.</li> <li>• Ambiguity surrounding the term "recovery," with multiple interpretations.</li> <li>• Treatment being viewed as the primary solution, but also as the primary issue.</li> <li>• Recovery being associated with mental hospitals.</li> <li>• Ineffective mental health programs.</li> </ul>
<b>Survivor</b>				
Sri Padma Sari, Murti Agustin, Diyan Yuli Wijayanti, Widodo Sarjana, Umi Afrikhah, Kwisoon Choe (2021)	This study investigates the mediating role of hope and the moderating effect of depression on recovery in individuals with Schizophrenia.	Cross- sectional design	This refers to a group of 115 individuals who have been diagnosed with schizophrenia and are from Central Java Province, Indonesia.	Depression moderated the relationship between hope and recovery, and hope mediated the relationship between depression and recovery.
Tegu Pribadi, Esther C-L Lin, Po- See Chen, Shih-Kai Lee, Reziki Fitryasari, Chih- Hsuan Chen (2020)	To assess the levels of internalized stigma and related factors among individuals with a diagnosis of schizophrenia in Indonesia.	Survey cross-sectional study	300 patients between the ages of 18 and 60 diagnosed with schizophrenia at an Indonesian mental hospital	In a study, it was found that almost one-third of the participants experienced moderate-to-severe levels of internalized stigma, with discrimination being the most significant type. Further analysis using multivariable ordinal logistic regression revealed that younger age, unemployment, and psychotic symptoms were risk factors for internalized stigma.

<b>Survivor (Cont.)</b>				
I Dewa Gede Candra Dharma; Ahsan; Retno Lestari (2022)	To explore and understand the meaning of life for schizophrenia survivors.	Qualitative, phenomenology study	There are five individuals who have survived schizophrenia and they are currently residing at Rumah Berdaya Denpasar.	The study identified eight main themes, which were: feeling cared for by others, being accepted by society, having a positive self-identity, the role of Ngayah in the recovery process, the importance of exploring one's abilities, recovering oneself, enjoying active socializing, and situations that affect one's abilities. The results indicate that these themes play a crucial role in mental health and well-being.
Suryani Suryani, Nurul Hidayah, Titin Sutini, Lilibeth Al-Kofahy (2022)	The purpose of this study is to describe the important aspects of the recovery process of Indonesian people living with schizophrenia.	An exploratory Study	Seven survivors who participated in the FGD were selected using purposive sampling technique.	Five themes arose from this study including becoming an agent of recovery, accepting yourself as you are, keeping a smile in all situations, seeking God's help as a way to get well, and ignoring by the government.
<b>Family</b>				
Retno Lestari, Ah Yusuf, Rachmat Hargono, Febri Endra Budi Setyawan, Ridhoyanti Hidayah, Ahsan Ahsan (2021)	To explore the experiences of rural residents in adapting to PWS in Indonesia	Qualitative research design dan interpretive phenomenological approach	Ten family members	Most of the participants believed that PWS induced alertness rather than fear. Furthermore, they mentioned that they were wary of similar situations and stressed the importance of preserving traditional beliefs and practices. Participants also highlighted the effectiveness of displaying indifference and combining traditional and modern health practices as suggested by spiritual leaders.
Watari Budiono, Kevin Kantono, Franciscus Cahyo Kristianto, Christina Avanti, Fauna Herawati (2021)	To compare the standard mental health care for schizophrenia in Indonesia with psychoeducation-enriched care for family members and investigate the family and patient parameters.	RCT	64 family members	Compared to the control group, the intervention group showed significant improvements in their perception of illness as well as a decrease in expressed emotion among family members. Patients in the intervention group also demonstrated a significant improvement in medication adherence ( $p < 0.001$ ), but only if their family members were part of the intervention group. Analysis using partial least-squares path modeling revealed that patients with family members who had low expressed emotion had higher medication adherence ( $\beta = -0.718$ ; $p < 0.001$ ).
Herlin Ferliana, Nyoman Anita, Damayanti, Diana Nurfarida Aisyah, Nuh Huda, Dwi Ernawati (2020)	This study aims to investigate the relationship between knowledge, perceptions, attitudes, support, and family independence in caring for patients with hebephrenic schizophrenia.	Correlational analytic design with cross sectional approach	57 family members	This research highlights the significance of family support in enhancing the self-esteem of patients diagnosed with schizophrenia. Consequently, it is anticipated that the hospital can enhance its patient recovery program that is centered around families.

<b>Family (Cont.)</b>				
Marthoenis, Marion C Aichberger, Meryam Sch ouler Ocak (2016)	To identify treatment seeking patterns and factors causing delays in psychiatric care access for early psychosis patients.	Qualitative	16 relatives of patients with schizophrenia and psychological distress are accompanying them in mental hospitals.	In many villages, mental disorders are believed to be related to a sickness or disease, commonly known as "village sickness". Therefore, families tend to take their loved ones to traditional healers before seeking help from mental health professionals. This can delay access to psychiatric treatment. Several factors contribute to this delay, such as misinformation or incorrect beliefs about the causes of mental illness, stigmatization, the role of extended family, financial problems, and long distances to psychiatric hospitals. Many families believe that it is essential for educated individuals to live closer to health facilities, to have prior experience with successful psychotic therapy, and for mental health awareness campaigns to be conducted in their communities.
<b>Service user and families</b>				
Herni Susanti, Karen James, Bagus Utomo, Budi Anna Keliat et al (2019)				
To gather feedback on the use and potential of Patient and Public Involvement (PPI) in mental health services in Indonesia, we aim to survey service users, families/ guardians.				
<b>Survivor and their families</b>				
Subandi M.A. (2015)				
To find out the recovery process for the first episode of psychosis in a Javanese cultural atmosphere				
Qualitative				
Seven psychosis patients and their families				
In the Javanese culture, recovery is a process that can be divided into three phases. First, the "rise" phase, which involves increasing one's insight. Second, the "effort" phase, which involves striving to achieve recovery. And third, the "rukun" phase, which involves harmonious integration with family and society. Participants in this process described their recovery in terms of physical movement, progressing from being confined to their homes to larger spaces with family and community. This enabled patients to achieve social recovery.				

## 4. Discussion

### ***The schizophrenia survivors' perceptions***

People with schizophrenia often experience delusions and hallucinations, as well as symptoms of depression. The study by Sari et al., (2021) highlights the importance of hope in the recovery of patients with schizophrenia. Patients who maintain a hopeful attitude towards recovery are more likely to experience a speedy and successful recovery, as well as a reduction in depression, due to their desire to return to their normal activities. Meanwhile, a study by Pribadi et al., (2020) found that one-third of 300 patients diagnosed with schizophrenia experienced moderate to severe levels of internalized stigma, which increases the likelihood of discrimination against them. Risk factors for discrimination

include younger age, unemployment, and psychotic symptoms (Pribadi et al., 2020). Therefore, nurses need intervention regarding stigma management and psychoeducation for people diagnosed with schizophrenia and their caregivers, such as family or the surrounding community. Research by Dharma et al., (2022) demonstrates that individuals with schizophrenia can achieve recovery, improving self-awareness, emotional control, and socialization. Healing is closely related to eliminating stigma in society. So, the patient needs to be accepted back by society, namely social recovery. According to Singla et al., (2020), people with schizophrenia may view recovery as a goal to reintegrate into society. This recent scoping review found 3 important needs from the survivors' perception: (1) to maintain a hopeful attitude towards recovery, (2) the acceptance to society, namely social recovery, and (3) need stigma management and psychoeducation.

### ***Family views on schizophrenia recovery***

Schizophrenia patients rely heavily on the support of their family members. Involving the family in the recovery process is crucial as the patient will interact with them. This is supported by research conducted by Ferliana et al., (2020), which highlights the importance of family support in boosting the self-esteem of patients with schizophrenia. To facilitate the recovery of schizophrenic patients, family members should be included in the program, equipping them with the knowledge and skills necessary to provide care and support for their loved ones, while also promoting their independence.

According to research conducted by Lestari et al., (2021) families still tend to resort to shackling patients with schizophrenia. In most cases, a local shaman or Balian is responsible for the treatment of the patient. However, it has been found that a combination of modern and traditional therapies is more effective for the recovery of schizophrenia patients. On the other hand, another study indicates that psychoeducation provided by mental health professionals is critical for the families of such patients (Budiono et al., 2021). Psychoeducation involves watching videos for two weeks on topics such as introduction to schizophrenia, stigma surrounding it, therapy options, expressing emotions, challenges faced by families, and understanding the patient's mood status.

### ***Health professionals' views on the recovery of individuals with schizophrenia survivors***

According to a research study by Tasijawa et al., (2021), schizophrenic patients face difficulties in recovery. The study also found that mental nurses show sincerity, willingness and make sacrifices in caring for the patients. They treat the patients wholeheartedly and consider them like their own brothers. However, the findings suggest that the patients view recovery as an unrealistic hope. Several studies have shown that nurses can impede the recovery process of patients due to their lack of understanding and negative attitudes towards recovery. Suryani et al., (2019) supports this finding, while Shean, (2009) suggests that healthcare professionals should adopt an optimistic approach towards their patients' recovery and help them lead productive and meaningful lives. van Langen et al., (2016) also highlight the importance of nurses recognizing and preventing patient relapses, empowering patients and their families, and being a good friend for patients to share their experiences openly. A study conducted by Mamnuah et al., (2019) in Indonesia revealed differing perspectives among healthcare workers regarding the meaning of recovery, with most of them not considering the recurrence of mental illnesses as a part of recovery that requires appropriate treatment. The study recommends that mental health policymakers establish specific standards to align healthcare workers' perceptions of the recovery and create effective strategies to help patients achieve recovery.

Psychiatric nurses offer an intervention to help schizophrenic patients recover through mindfulness therapy. According to Astuti et al., (2020) research, this therapy is significantly effective in increasing hope and recovery rates in schizophrenia patients. The therapy is divided into several sessions, which include training in deep-breathing relaxation techniques to promote relaxation, self-awareness sessions to increase awareness of the environment around them (such as time, place, and people), self-compassion sessions to reduce negative self-assessment, and acceptance sessions to acknowledge and believe in the possibility of recovery.

## 5. Conclusion

After reviewing 13 articles, this recent study highlights the perceptions of survivors, families, and health professionals regarding schizophrenia recovery. The findings suggest that mental health policymakers should establish clear standards to ensure that perceptions of schizophrenia recovery are balanced. This will aid in the development of effective strategies to help patients achieve recovery. This scoping review discusses the important aspect in fasten the process of recovery toward the Schizophrenia' patients. Not only understanding and attitudes during the recovery, the health providers must show sincerity, willingness and make sacrifices in caring for the patients. Being good friends with the survivors may lead the patients to share their experience and feelings openly.

## Conflict of Interest

The authors declare no conflicts of interest for the results.

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**Cite this article as:**

Widianti, E., Hidayati N.O., Rafiyah I., Kusumah I. (2023). Perceived of Survivors, Families, and Health Professionals on the Recovery Process of Schizophrenia in Indonesia: A Scoping Review.

GHMJ (Global Health Management Journal), 6(2). 90–99. <https://doi.org/10.35898/ghmj-62975>