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Qualitative Research



The need to achieve recovery for people with schizophrenia in the community: Service user and family perspectives

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Abstract

Objectives: This study aimed to describe the need to achieve recovery for People with Schizophrenia (PwS) in the community based on the perspective of service users and families.

Methods: This study was conducted through descriptive qualitative research. Three PwS groups and three family groups, with a total of 15 PwS and 16 families, were recruited through purposive sampling. Data collection was conducted through focus group discussions. The data analysis technique used was framework analysis.

Results: The study found two main themes: The perception of recovery and the need to achieve recovery. Perceptions of recovery include criteria for recovery, optimism in achieving recovery, and the benefits of recovery. The needs to achieve recovery include the psychological needs of PwS, family support, community support, and the support of health workers.

Conclusion: There were still PwS and their families who did not yet have the optimism to recover. It is necessary to develop interventions that take into account the perceptions and needs of PwS to achieve recovery. **Keywords:** Needs; perception; qualitative research; recovery of function; schizophrenia

Schizophrenia is a chronic, complex, and serious mental disorder because it causes disabilities in various domains of function, namely cognitive function, perception, emotion, and social interaction.^[1,2] Its prevalence reaches 0.3% of the global population or experienced by 20 million people in 2017.^[3,4] A systematic review of 73 studies published in 1990–2015 states that the prevalence of schizophrenia per year is 0.39–0.40%.^[5] The prevalence of schizophrenia in Indonesia in 2013 based on Basic Health Research (Riskesdas) was 0.17% and in 2018 was 0.18%.^[6] The aforementioned data show that the prevalence of schizophrenia in Indonesia in 2013 to 2018.

Schizophrenia was originally considered a degenerative condition with a poor prognosis, yet it is beginning to shift toward the hope of recovery.^[7,8] Recovery is traditionally defined as the remission of both positive and negative symptoms. Recent approaches shift toward improving quality of life through improved emotional, social well-being, and individual as well as functional recovery (Gonzalez-Flores, 2018). The recovery process can also reduce relapse and help people with schizophrenia (PwS) lead productive and rewarding lives.^[9] Thus, the assumption that PwS cannot be recovered is no longer relevant.

The main purpose of recovery is to achieve remission of symptoms and independence in performing functional abilities. Symptom remission is defined as a condition in which PwS is free from positive or negative symptoms,^[10,11] and can be achieved by about 50% PwS.^[12] A study of 223 schizophrenic and schizoaffective followed up for 6 months by Cipto Mangunkusumo Hospital (RSCM) Jakarta showed that the remission rate reached 61%.^[13] Independence of functional abilities is based on the ability to care for themselves, maintain activ-

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ity in daily living (ADL), socialize, and work. This capability is successfully achieved by approximately 20.5% PwS.^[14,15] The above-mentioned data show that there are still many PwS who have not been able to achieve remission of symptoms and independence in functional abilities.

The low rate of remission of symptoms and independence of functional abilities pose a heavy burden for families because treatment of PwS depends on family members.^[12,15] PwS treatment causes families to lose time to work, in addition to the high cost of care or treatment incurred.^[16,17] The state also bears the burden of PwS health care costs. Mental disorders accounted for 4.5% of the total disability-adjusted life years by ranking fifth but were ranked first with a contribution of 13.4% to the total YLDs (years lost due to pain or disability), and schizophrenia ranks as the third largest percentage of mental disorders after depression and anxiety.^[18] Thus recovery is a pivotal need for PwS, families, and the country.

The paradigm of PwS recovery can be viewed from a clinical perspective as well as a subjective perspective. The recovery criteria from a clinical perspective include symptom remission and improvement in functional abilities on a daily basis, while the recovery criteria from a subjective perspective can be a self-assessed and self-reported feeling of well-being by the person concerned. The subjective perspective is critical to consider and can complement the final assessment of functional ability, although the subjective perspective is not always in line with the clinical perspectives will result in a more accurate and thorough assessment of recovery.

The PwS recovery rate is still relatively low. Some studies reported recovery rates of 19.86% and 10% during 6 months of observation, which then decreased to 7.53% and 1% within 1 year of observation.^[11,21] Another study showed that the PwS recovery rate during 3 years of observation was 51.7% in the 1st year, 35.0% in the 2nd year, and 44.3% in the 3rd year.^[22] This shows that the recovery rate of PwS in the first 6 months of treatment is better than in the 1st, 2nd, and 3rd years.

The success of recovery is not only affected by treatment compliance factors but also by psychological and social factors. Psychological factors include optimism for recovery, resilience,^[23] high intrinsic motivation,^[21] and coping strategies.^[19] PwS who use mental health services explain some of the components that help them during the recovery process, namely the belief that they can recover, hope for a better future, self-esteem, confidence, a sense of belonging, and having a purpose in life to be independent.^[24] Meanwhile, social factors that affect recovery include the elimination of stigma,^[20] positive family relationships and support,^[23] peer support, strong health worker relationships with clients, as well as social support.^[21] Stigma can hinder recovery because it will lead to negative self-es-

What is presently known on this subject?

 Schizophrenia was initially considered a degenerative condition but is now shifting to recovery. The recovery has shifted from remission of positive and negative symptoms to improved quality of life. It is influenced not only by drug compliance but also by psychological and social factors. This study was conducted to explore the need to recovery from the perspective of people with schizophrenia and their families.

What does this article add to the existing knowledge?

• This study showed that there are still some families that are not optimistic that their members can recover from schizophrenia, even though there is still health workers' communication that breaks their hopes.

What are the implications for practice?

 Cultivating optimism and motivation is the key to achieving recovery. People with schizophrenia need the trust and support of their families and communities to socialize and work to recover.

teem in the patient and trigger pessimistic feelings to recover. ^[20] The family has a very vital role in the recovery process of its members with schizophrenia to lead a productive and integrated life in society.^[23] PwS recovery can be enhanced through strengthening psychological and social support.

The research will be conducted in Central Java because Riskesdas 2018 shows that Central Java province has the 4th highest prevalence of schizophrenia and psychosis in Indonesia, which is 0.25%. This number exceeds the 0.18% national prevalence. ^[6] The percentage of people with severe mental disorders who get mental health services according to minimum service standards in Central Java is 83.1%. The regencies and cities that have the lowest rate are Sukoharjo Regency (38.2%) and Surakarta City (44.7%), meaning that the percentage of people with mental disorders who have obtained standard services is still far from the target.^[25]

Research that will develop an intervention will be more effective if the research subjects or respondents are actively involved in the research phase, particularly during the development of intervention models. The development of intervention models, especially empowerment models put forward the bottom-up process. This process is carried out through the need assessment activities of research respondents by exploring their perceptions of the problems encountered and the need to overcome these problems.^[26,27] The purpose of this study was to describe, from the viewpoint of service users and families, what is required to help PwS recover in the community.

Materials and Method

Type and Design

The study was qualitative research with a descriptive-qualitative approach. It used inductive strategies to interpret the characteristics of complex clinical phenomena. Interpretation is the search for truth, explanation, understanding, and meaning in the relationship of cause and effect.^[28] The study's design was used to explore the perceptions of PwS and families about recovery and the need to achieve it.

Place and Date

The study was conducted in Central Java, Indonesia, specifically in Sukoharjo Regency and Surakarta City, for 4 months (October 2022–January 2023), starting from the administrative process to the implementation of data collection.

Population and Sample

Participants consisted of 3 PwS groups and 3 family groups; each group consisted of 4-8 people, for a total of 15 PwS participants and 16 families. The participatory sampling technique used in the qualitative design was purposive sampling. PwS participants were medically diagnosed with schizophrenia, aged 19-59 years, had been hospitalized, lived in the community with family, had no relapse in the past 3 months, were cooperative, could communicate well, and were able to give written consent. PwS exclusion criteria are using drugs, experiencing mental retardation, and having a physical illness that leads to disability. PwS family inclusion criteria are: Living with PwS and providing face-to-face care for at least 10 h/day; age 19-59 years; being able to communicate well; being physically and spiritually healthy; and being able to give written consent. Recruitment is carried out by the person in charge of mental health at the Public Health Center (Puskesmas) by providing a list of PwS in the region that meet the inclusion and exclusion criteria and then approaching prospective participants to provide an explanation of the research information. After giving them 24 h to consider their decision-making, researchers obtain informed consent and invite them for focus group discussion (FGD).

Data Collection Tools

FGD guidelines were employed by the researchers. The guideline contains a group discussion topic covering PwS and family perceptions of recovery (what they know about recovery, criteria, and optimism to be able to recover) and the needs to recover (PwS intrinsic factors, family support, community support, and expected healthcare support). During the data collection phase, researchers also used writing instruments and voice recorders to record data and significant items.

Data Collection Process

Data collection used the FGD method by discussing their perceptions of the recovery of PwS in the community and the need to achieve recovery. There are three PwS groups and three family groups (one group in Sukoharjo Regency and two groups in Surakarta City). FGDs were carried out in 60–90 min. There was a facilitator guiding the discussion and assistant taking notes on important events, such as non-verbal aspects or interactions in groups, and recording discussions. Next, the recordings were organized verbatim.

Data Analysis

The data analysis technique used by researchers was framework analysis.^[29] Framework analysis includes 7 stages. The first stage is transcription; the researcher writes the recorded discussion into a transcript. The second stage is familiarization; the researcher reads the transcript several times to understand it better. The third stage is coding; the researcher makes codes on several information-rich transcripts. The fourth stage is developing a working analytical framework; the researcher creates an analytical framework. All codes obtained in the third stage are organized into categories. The fifth stage is applying the analytical framework. An analytical framework is applied to all transcripts using existing categories and codes. The sixth stage is charting data into the framework matrix; the researcher creates a matrix and the data are mapped into the matrix. Charting summarizes data by category from each transcript. The seventh stage is data interpretation.

Dimension of Research Ethics

This research protocol has been declared to have passed the ethics assessment by the Ethics Committee of the Faculty of Nursing, UI with the number KET-236/UN2.F12.D1.2.1/ PPM.00.02/2022. All research subjects have signed a consent sheet after being given research information. Researchers have explained that participation in this study is voluntary; there is no element of coercion, and they can refuse to participate or resign at any time without affecting the health services they receive from Puskesmas. The subjects were given permission for voice recording during the data collection process.

Results

Characteristics of Participants

Participants consisted of two groups, namely PwS with as many as 15 people (Table 1) and PwS families with as many as 16 people (Table 2).

Table 1 showed that PwS participants were mostly male (67%), high school graduates (67%), unemployed (60%), and unmarried (60%). The health facilities used for checking up were Puskesmas (46.7%) and hospitals (46.7%), and there was 1 participant who did not checking up. The age of PwS ranged from 24 to 64 years, with an average age of 46 years (standard deviation [SD]=12.7). The illness lasted from 4 to 34 years, with an average of 18 years (SD=10.8).

Table 2 showed that the majority of families were female (62.5%), high school graduates (43.8%), housewives (31.3%), married (68.8%), and parents of PwS (37.5%). The age of the family participants ranged from 19 to 74 years, with an average of 51 years (SD=18.8). The duration of treating PwS ranged from 1 to 44 years, with an average of 15 years (SD=13.3).

Table 1. Characteristics of participants of people with schizophrenia

Chave stavistics	F	0/
Characteristics	F	%
Gender		
Male	10	67
Female	5	33
Education		
Not completed elementary school	3	20.0
Elementary School	1	6.7
Middle School	1	6.7
High School	10	66.7
Job		
Unemployed	9	60
Seller	2	13
Parking attendant	2	13
Tire patcher	1	7
Screen printer	1	7
Marital status		
Married	4	27
Unmarried	9	60
Widow/Widower	2	13
Health facility		
Puskesmas	7	46.7
Hospital	7	46.7
Not checking up	1	6.7
Total	15	100
E. 7777777777777		

PwS and Family Perceptions of Recovery

The theme of ODS perception and resistance to recovery is composed of three categories: recovery criteria, optimism to achieve recovery, and recovery goals.

Recovery Criteria

PwS are said to have achieved recovery if the symptoms of the mental disorder have diminished.

"Yeah, it's pretty good; it's a little bit better. Usually dirty talk or cursing, just going into his room is thought to be poisoning, something like that. Now the chicken coop has been removed." (K16)

The next criteria to recover are PwS can do self-care.

"I mean, wake up, take a shower, drink, eat, and clean the room; those activities were recovered, and I am grateful." (K15)

In addition to taking care of themselves, the criteria for recovering are being able to carry out daily activities.

"It means someone who has been able to do daily activity as usual." (K1)

The next criterion is to be able to communicate and socialize with family and the surrounding community.

Table 2. Characteristic of the participant's family			
Characteristics	F	%	
Gender			
Male	6	37.5	
Female	10	62.5	
Education			
Not completed elementary school	1	6.3	
Elementary school	6	37.5	
Middle School	1	6.3	
High School	7	43.8	
University	1	6.3	
dof			
Teacher	1	6.3	
Housewife	5	31.3	
Private	2	12.5	
Seller	3	18.8	
Housemaid	1	6.3	
Retiree	1	6.3	
Guide	1	6.3	
Driver	1	6.3	
Laborer	1	6.3	
Marital status			
Married	11	68.8	
Unmarried	4	25.0	
Widow/Widower	1	6.3	
Relationship with PwS			
Parent	6	37.5	
Husband/wife	1	6.3	
Sibling	5	31.3	
Uncle/aunt	1	6.3	

Table 2. Characteristic of the participant's family

PwS: People with schizophrenia.

Child

Total

Nephew

"Get along with the neighbors" (P4)

PwS are said to recover if they can return to work.

"Yes, they can help running errands at home." (K8)

Other criteria for recovery are being able to take responsibility, play their role, be happy, passionate, independently meet needs, not depend on drugs, and get away from traumatic experiences.

2

1

16

12.5

6.3

100

"I think the most important thing is being responsible with himself. If he can take responsibility for himself, he's recovered. It is because maybe what he does must have its own rules. If he is able to take responsibility for himself, insyaallah he will be recovered." (K7)

Thus, the criteria for recovery according to the participants are remission, ability to self-care, perform activities, and work.

Optimism toward Recovery

Participants' perceptions of PwS opportunities toward recovery differ. Some participants, who were PwS and their families, were optimistic that they could achieve recovery. They submit themselves to God while taking regular medication. PwS recovery also depends on their own.

"It depends on himself. Who can cure it is himself." (K9)

Some families believe that PwS cannot recover because there have been disorders since birth or early childhood.

"It can't because it's been since early childhood; from the age of 10 months, mother and father were still healthy until they died." (K15)

Some families are still in doubt about whether PwS can recover.

"Yes, it is still partially, but what is it, I hope he can recover before I die; he can be independent." (K11)

There are families who thought PwS can recover quickly after taking expensive drugs.

"Sometimes I see someone who recovers quickly; he uses expensive drugs. If we are using KIS, is it different?" (K3)

Thus, there are still some families that are not optimistic that their members can recover from schizophrenia because they have been treated in the long term but have not shown any progress.

Recovery Goals

The family hopes that if PwS recovers, they will be able to take better care of themselves, communicate, socialize, and carry out their role in the family.

"The benefit for himself is being able to organize himself better. So that he can take a shower or maintain personal hygiene. It is also glad to see that he has recovered; it is also good to talk to someone healthy. If he can do it by himself, he won't bother anyone else. Maybe something like that. The child can be more loved too, given more attention, right? The child feels happy knowing that his mother is fully cured and already healthy." (K1)

The family also feels happy if ODS recovers because it can ease the burden that has been felt by the family, both subjective and objective burdens.

"Yes, it lessens the burden; for example, now that I'm married, he'll be left safe if I want to visit my in-laws. But if he still relies on me for everything, I cannot move or go out of the house; the point is like that, hehe." (K15)

Hence, the goal of recovery for PwS is to be able to take care of, socialize, and fulfill its role in the family. As for the family, recovery can reduce the burden felt.

The Need to Achieve Recovery

The needs to achieve recovery include the psychological needs of PwS, family support, community support, and the support of health workers.

Psychological Needs of PwS

PwS will soon achieve recovery if there is self-confidence and motivation, in particular intrinsic motivation.

"Yes, maybe... being optimistic is the first way that I can get well, and it is implanted in him so that he can be encouraged. He is like, Oh, I am sick and must be able to recover.' Then he has the spirit to be able to recover, and what is next is confidence because if something like that happens to him, his confidence is down." (K1)

The presence of hope in life can also increase PwS's motivation to recover.

"If later I work, it is for anything, for savings, and for my child to be happy, to eat, for everything." (P13)

In addition, the coping skills that PwS has also affect the recovery process.

"Hard at work." (P3)

And then the power of good (self-insight) is an important key for PwS to undergo the recovery process.

"What is hard is when the sick sometimes does not feel that he is." (K4)

The psychological aspects that are needed to recovery are intrinsic motivation, coping strategy, and good self-insight.

Family Support

PwS need family support in the form of being helped to control schizophrenia if it relapses, inviting them to communicate, and involving them in family togetherness.

"Maybe it's more intense to invite talking because everything comes to mind for people with mental disorders. If there is no one to talk to, they usually daydream or see others. Well, that will make his mind more unhealthy. That's it." (K1)

"Family gatherings can encourage them because they are always happy in every meeting. They can gather, eat together, and continue to be able to share complaints." (P6)

They also want to be involved in household chores and have motivated self-care.

"I remind him, let's change clothes, change pants, change hats, then play." (P12)

help withIn addition, families also need to help with PwS treatment, provide autonomy, and provide motivation.

"The support...like motivational support, spirit support. At least we embraced him so that he can motivate himself, so it radiates." (K7) The family support needed for PwS recovery is primarily emotional support and instrumental support in the form of communication and family unity.

Community Support

The form of community support that can be given to PwS is to accept their conditions, invite them to communicate, invite them to join activities, and not isolate them.

"Yes, he is invited to chat. Handle it normally, and don't isolate them." (K2)

The community also needs to give attention and job opportunities to PwS to make them productive again.

"Sometimes they are invited to the head of the village, given a job, told to clean up the garden, and told to work as construction laborers too." (K3)

Thus, the public support needed for PwS recovery is to communicate, engage in social activities, and not give stigma.

Health Worker Support

The support of health workers is needed by PwS and their families. A necessary form of support is therapeutic communication. The communication of health workers greatly influences the motivation of PwS and their families to undergo treatment and care to achieve recovery.

"Maybe from the health facility. The medical team might be able to understand better; for example, when the nurse just came, the nurse was not friendly, and sometimes how the doctor talks is just like what K4 said. The words were not good, unkind, and so on. It can affect the patient." (K1)

Poor communication from health workers can break PwS and family hopes of recovery.

"Yes, ma'am, that was once. So we want to find out whether it can be recovered, yet they deny it." (K4)

Health support for PwS recovery is therapeutic communication and arouses hope for recovery.

Discussion

Perception of Recovery

Recovery criteria based on participants' perceptions include many aspects: Being able to control symptoms, taking care of themselves, doing ADL, socializing, returning to work or school, forgetting traumatic experiences, independently meeting needs, having responsibilities, having good self-esteem, and not relying on drugs. This criterion is in line with the theory that indicators of recovery are remission of symptoms and recovery of functional abilities, which include self-care functions, socialization, independence, no relapse, no drug dependence, and work or school productivity.^[11,21,30,31] The PwS recovery rate based on symptom remission criteria reached 59.9%, while based on clinical criteria (symptom remission, adequate function, independent living, social function, work or school full-time), the recovery rate reached 31.7%.^[30] This recovery criterion is vital to be socialized so that PwS, families, cadres, and nurses can identify whether recovery has been achieved or not.

While some participants thought that schizophrenia could not recover because the disorder had started in childhood and did not always get better, the majority of participants were hopeful that PwS could recover, even though it would take a while and not be as perfect as before the illness. There are also participants who are still in doubt. These findings are in line with other studies showing that schizophrenia is chronic, but families expressed hope for a complete cure for sick relatives and a strong belief that they will be able to return to society. The family has full hope and motivates sick relatives to undergo treatment without despair.^[32] The presence of hope or optimism to recover is the main key in achieving recovery, and conversely, pessimism has the potential to harm and hinder recovery.^[30] Growing optimism for PwS, families, and health workers is very crucial because it is the main determinant of whether they want to run the recovery process.

The goal of recovery is categorized into four: PwS, family, community, and health workers. The goal of recovery for PwS is to control emotions, increase self-confidence, be able to play a role, live independently, be productive, reduce stigma, and return to society. The goal of recovery for families is the creation of calm, less burden, and less stigma. The goal for the community is to create a sense of security, while for health workers is to achieve satisfaction and selfactualization. These findings are in line with the theory that based on the PwS perspective, recovery means gaining and maintaining hope, understanding one's abilities and disabilities, being actively involved in life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self. The goals of the principles of recovery-oriented mental health practice are to ensure that mental health services support the recovery process, recognize that recovery is not always about healing but about having the opportunity to choose and live a meaningful life and become a valued member of the community, and accept that the results of recovery are personal and depend on the individual.^[33] The PwS will determine the goals to be achieved to be actively involved in the recovery process.

The Need to Achieve Recovery

The need to achieve recovery includes four components, namely PwS psychological needs, family support, community support, and health worker support. PwS psychological needs required to achieve recovery include expectations, self-

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-esteem, coping skills, motivation, self-insight, and spirituality. This is in line with research showing that hope is a major component that will accelerate the recovery process and is a protective factor for vulnerability to stress and stigma.^[34] Intrinsic motivation is a predictor of recovery achievement with an OR of 1.68,^[21] while self-esteem is a factor that mediates the relationship between stigma and recovery from a subjective perspective.^[20] The psychological needs of PwS are a major determining factor of achieving recovery.

Family support is a key requirement for recovery. Support can be provided by helping to control symptoms, involving PwS in household chores, assisting with treatment, motivating, giving autonomy, inviting communication, inviting refreshing, supporting productivity, and maintaining togetherness. These findings are in line with research showing that families have an influential role in the clinical outcomes and recovery of PwS. Families can foster the hope and spirit of PwS to achieve recovery, but conversely, families that show high emotional expressions such as criticism, excessive involvement, and hostility will trigger relapse.^[35] Another study found that 60.1% of participants received a negative impact from the family because they were forced to do treatment, considered a disgrace, causing family grief or fear, and as many as 29% of participants stated that they were shunned by relatives because they had a mental disorder.^[36] Thus, the recovery intervention needs action; hence, the family can provide appropriate support to create a conducive environment for PwS recovery.

Community support is also a pivotal component needed in PwS recovery. Community support can be done by accepting ODS conditions, inviting them to do activities, inviting them to communicate, not isolating, and providing job opportunities. This is in line with other research that says everyone has a responsibility to support people with mental health problems, one of which is the community. Society plays a role in providing emotional support, encouraging autonomy, and facilitating PwS.^[37] On the contrary, the stigma of society internalized by the patient will degrade his quality of life.^[38] Community support is needed to accelerate PwS recovery.

The support of health workers is needed by PwS to achieve recovery. Support can be provided by providing professional care, conducting therapeutic communication, providing treatment, and not breaking the hope of recovering from PwS and family. This finding is in line with research showing that health workers play a role in providing medical and psychosocial services, assisting recovery, acting as mediators between PwS, families, and the government, providing advocacy to PwS and families, sharing knowledge, and reducing stigma by raising awareness.^[37] The support of health workers is required because PwS and families need medical and psychosocial therapy to achieve recovery.

Limitations

Participant characteristics in terms of age vary widely and are less homogeneous for both PwS and their families. Long-term suffering from schizophrenia also has a wide range, including family care experiences. Future research should make a more homogeneous group setting, research carried out in several provinces so that more representative of Indonesian culture.

Conclusion

There are still some patients and families who are not optimistic that schizophrenia can recover. Recovery interventions are required that take into account the perception and needs of recovery according to the person with schizophrenia and their family. Nurses should educate PwS and their families that schizophrenia can be recover as long as optimism and enthusiasm lead the process. Nurses' communication should be able to motivate PwS to recover, rather than breaking their hopes.

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