The Indonesian Survivors' Perspective about Recovery from Schizophrenia: An Exploratory Study

Suryani Suryani[1]*⦿**, Nurul Hidayah**[1]⦿**, Titin Sutini**[1]⦿**, Lilibeth Al-Kofahy**[2]⦿

[1]Faculty of Nursing, Universitas Padjadjaran, Bandung, Indonesia
[2]Sam Houston State University, Texas, United States

Abstract

Background: Recovering from schizophrenia is a unique process and is influenced by the cultural background of survivors.
Purpose: The purpose of this study is to describe the important aspects of the recovery process of Indonesian people living with schizophrenia.
Methods: This study used qualitative exploratory descriptive and data were collected through focus group discussion with seven participants at a Residents office on July 2018. Data were analysed using the theory of Braun and Clarke to identify key themes.
Results: 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.
Conclusion: It was concluded that, in the process of recovery, survivors became agents of recovery, so patient-centred care becomes very important in providing nursing care to the survivors. The result of this research can be considered for community nurses in caring for schizophrenia survivors.

Keywords: qualitative; important aspects; recovery; survivor experience; schizophrenia.

Introduction

Recovery from mental illnesses, especially schizophrenia, is not only a process of returning to premorbid level of functioning and asymptomatic phase of the person's life (Jacob, 2015), rather, it is a long journey that is full of twists and turns and back and forth, sometimes healed, sometimes relapsing (Jacob, 2015; S Suryani, 2013). During the recovery process, individuals will face various challenges and obstacles due to their limitations as a result of the disease.

Recovery is a non-linear process and goes through different stages for each individual (Hancock, Smith-Merry, Jessup, Wayland, & Kokany, 2018). Through the recovery process, the individual will regain the ability to control his/her life, the ability to function socially, and feel more welcome in the family and in the community. Recovery is felt complete when they no longer need drugs and symptoms of the disease are minimal (Jose et al., 2015).

A qualitative study conducted by Wood, Price, Morrison, and Haddock (2010) on the concept of recovery in the perspective of patients found that the key to the success of the recovery process is the alleviation of symptoms and or negative emotions. Other important aspects are motivation, independence, individual coping and dangerous behaviour changes. Another study by Subandi (2015) found three steps of the recovery process according to his participants, including gaining insight; struggling to achieve recovery; and harmonious integration with family and community integration. In many Western countries such as England, Australia and the USA, the concept of recovery in people diagnosed with schizophrenia has been developed and implemented. As a result, many people with schizophrenia have recovered and played a role in the community. They are even becoming an expert by experience, such as the members of the Hearing Voices Network, an international organisation of people with hearing voices. Recently, in Australia

(at the Central Queensland University), there has been an innovation in implementing the concept of recovery, where psychiatric nurses played a key role to make it a reality (Happell et al., 2014). Recovery as a discipline of life experience has been developed to support the application of the recovery concept into services (Byrne, Happell, & Reid-Searl, 2015). In Asia, the concept of recovery has also been developed in several countries such as China, Singapore, the Philippines, Malaysia, Thailand and Indonesia. However, in Indonesia, the recovery concept is still not well-implemented due to a lack of support from the government and community.

The recovery process does not always run smoothly. There are several factors that can support and inhibit it. In general, it can be categorised into two factors, namely personal and environmental factors. Personal factors that support recovery in both Western and Eastern countries are self-acceptance (Hancock et al., 2018; Kaewprom, Curtis, & Deane, 2011) coping (Roosenschoon, Kamperman, Deen, Weeghel, & Mulder, 2019; Woods, Hart, & Spandler, 2022), and adherence to the treatment (Kaewprom et al., 2011). What's different is that in Eastern countries religious beliefs also support recovery (Dein, 2017; Subandi, 2015; Suryani Suryani, Welch, & Cox, 2013), while there are some personal inhibiting factors in both Western and Eastern countries, including severity symptoms (Kaewprom et al., 2011; Van Eck, Burger, Vellinga, Schirmbeck, & de Haan, 2018) and negative symptoms (Ventura et al., 2015).

Supporting factors from environmental aspects in both Western and Eastern countries are family and community, which provide for personal growth and developing resilience to stress (Jacob, 2015; Kaewprom et al., 2011; Naheed, Akter, Tabassum, Mawla, & Rahman, 1970),while the main supporting factors in Western countries are the quality of mental health services (Data, n.d.; Perkins & Slade, 2012). In contrast, the most common inhibiting factors in both Western and Eastern countries is stigma about mental illness (Andika, Syahputra, & Marniati, 2017; ANGERMEYER & SCHOMERUS, 2012; Avdibegović, E., & Hasanović, 2017; Vass et al., 2015). However, there is another factor that inhibits recovery in Eastern countries, that is the inadequacy of the available services caused by lack of political will and resources (Rathod et al., 2017).

Regarding the application of the concept of recovery in mental health nursing services, since 2013, we have conducted several studies such as life experiences of patients with schizophrenia, factors related to relapse of patients with schizophrenia, family experiences in caring for an individual with schizophrenia, family perceptions of schizophrenia and perceptions of clients, families, policymakers and community health staff about recovery. From these studies, we conclude that there are many factors associated with the recovery of schizophrenic patients, namely the individuals themselves, family, environment or community, policymakers and

mental health services. So a comprehensive study is needed to find a recovery model in schizophrenia patients in Indonesia.

Our recent research "recovery model for Indonesian people with schizophrenia" aims to develop recovery models for individuals who experience schizophrenia in Indonesia. With regard to the recovery model development, several activities such as approaches to community health centres, community leaders and cadres have been carried out. Peer and family support groups have been formed. Counselling has been done several times to the community where this research was conducted. Workshops for family support groups have been carried out, and training for cadres has also been conducted. Furthermore, the person in charge of mental health programmes in community health centres and mental health cadres as well as the role of policymakers and community in supporting the recovery process of individuals with schizophrenia were evaluated through qualitative research. Evaluation of recovery processes experienced by survivors with schizophrenia has also been done.

Individuals who experienced schizophrenia have the opportunity to recover from their illness. Many survivors in several countries proved that they can recover from schizophrenia, although many also do not recover and often relapse. Therefore, understanding about what makes the survivor recover from schizophrenia and live more productively is needed. This study aims to describe the Indonesian survivors' perspective about recovery from schizophrenia. The findings of the study will add new knowledge about aspects related to the recovery process.

Methods

Design

This study used a qualitative exploratory descriptive to answer questions about experience of recovery from schizophrenia (Hammarberg, Kirkman, & de Lacey, 2016). The qualitative exploratory descriptive is considered appropriate as it allowed the researchers to gain a deep understanding of the experiences of survivors in the process of recovery. Participants and Setting

A focus group discussion (FGD) was conducted to obtain information from participants, who were selected using a non-probability sampling technique with a purposive sampling method (Clarke, V., & Braun, 2013). Seven survivors who participated in the FGD were selected using purposive sampling technique. The inclusion criteria were as follows: survivors diagnosed with schizophrenia but have been declared stable by a mental specialist from the West Java Psychiatric Hospital, had no impaired cognitive function (measured using mental status assessments), have good insight (measured using the standard mental status examination), and can communicate well and cooperatively. Participants were contacted in person by the lead researcher
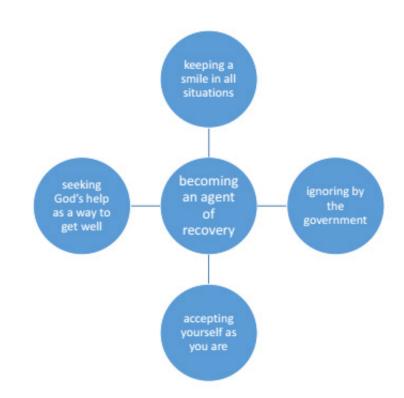
Figure 1. Five Themes in This Study

through the outpatient unit of the Melong Community Health Centre, South Cimahi, West Java, Indonesia. At the time, the participants were informed that they needed to be assessed by the attending psychiatrist to ensure that they met the inclusion and exclusion criteria for involvement in this study.

Ethical consideration

Ethical clearance was obtained from the Ethics Committee, Faculty of Medicine, Padjadjaran University, with number 627 / UN6. KEP / EC / 2018. Before starting the FGD, the researchers explained the study to all participants, and then they were asked to sign the consent form manually.

Data collection

Information was gathered through an FGD on 17 July 2018. Some people might find it difficult to express their feeling or opinions. Sometimes, it takes listening to the opinions of others in a small and safe group setting before they form thoughts and opinions. Focus Group Discussion as data collection methods and techniques in social research and as part of a participatory approach to identify the circumstances, needs, problems and potential development opportunities into the community and social capital in development, can reveal a wealth of detailed information and deep insight (Wilkinson, 2011). When well-executed, a focus group creates an accepting environment that puts participants at ease, allowing participants to thoughtfully answer questions in their own words and add meaning to their answers. The FGD was conducted for 1.5 hour, and all participants were able to express their experiences and opinions well. However, some needed a reiteration of the questions from the moderator. At the beginning of the FGD, the participants were no longer shy and hesitant after the facilitator encouraged them. In the last session of the FGD, the moderator summarised the results of the discussion for the participants to validate.

Data analysis

Data were analysed using the theory of Clarke and Braun (2013) to identify key themes. The first step was to familiarise the data. This was accomplished by transcribing the conversation, reading and re-reading the data, and then underlining the main point. This process gave the researcher a general sense of the participants' experiences. Then, the researcher commenced the process of identifying significant statements which captured the core elements of the participants' experiences. The next step was sharing the initial code. The researcher looked for common categories or themes across the entries for each question. We asked several people to participate in this process, including all researchers and some participants. After that, the researchers reviewed the theme to check whether it works in relation to extracting the code (stage one) and the entire data set (stage two) and then produced thematic maps of the analysis. Finally, the researchers defined and named the theme; in this stage, the researchers analysed each theme continuously for improvement and then made a report (Clarke, V., & Braun, 2013).

To maintain strictness in data analysis, bracketing was employed in the analysis process to understand the experiences of the participants as they truly were. The researchers reviewed each of the participants' significant statements and assigned meaning to each. This required the consideration of both the explicit and implicit meanings inherent in each statement. This involved two fundamental processes: intuiting (eidetic comprehension or accurate interpretation) and reflexivity (moving backwards and forward between the participants' statements to the initially formulated meanings developed) until the researchers were satisfied that the formulated meanings were an accurate reflection of the intended meanings of the participants.

Results

The number of participants in this study was seven survivors diagnosed with schizophrenia: four men and three women. The level of education of survivors varied from primary, junior and senior high school. Four of the participants were not married and do not have a job. They lived with their parents. While three of them were married and have a part time jobs. The survivors' age ranges from 22 years old to 47 years old, and the average length of illness is between 10–15 years. Five themes arose from this study as can be seen in the figure below:

Becoming an Agent of Recovery
This theme means that the survivor is the person who plays the most important role in the recovery process. The survivor is the central point in his or her recovery instead of the therapist. This theme is confirmed by all participants in this study. All participants agreed that, to be able to recover from schizophrenia, they must be the one who takes the responsibility to recover. One of the participants stated, '…*my own responsibility, yes… I have to work and earn money. I have to help myself*'. Another participant stated, '*I have to recover from this illness… I have to be an agent recovery of myself*'. This theme is also supported by the statement of another participant, saying '*every survivor has a different experience in overcoming the pain and stress. They have their own way to recover… and… they have to be responsible for their own health*'.

Keep Smiling in All Situations
This theme was proposed by one participant who revealed that healing can be achieved by making yourself and others happy by smiling. Although not all participants (four participants) expressed this feeling, the researchers considered this theme as a very significant aspect in supporting the recovery process. A smile is the distinctive characteristic of the Indonesian culture, especially of the Sundanese people who always prioritise the importance of compassion by always smiling to everyone in every situation.

During the recovery process, the survivor felt that a smile possessed an extraordinary power. Smiles can make someone see the world more beautifully, and a sincere smile can melt a frozen relationship, encourage people who are desperate and create a bright atmosphere in an interpersonal relationship. Smiling can become a spirit of energy that makes survivors feel accepted by others around them. One participant said that healing can be obtained by making yourself and others happy with a smile, stating '…*your smile heals, if you see people smile, it feels pleasing, if you receive smiles from other people and we also have to smile*'.

Accepting Yourself as You Are
Almost all participants (six participants) in the FGD confirmed that 'accepting yourself as you are' is an important aspect in their recovery. A participant said that is how she was able to accept her condition. She said that having a strong commitment to not think about the past is a way of accepting your present condition. She stated, we '…*must accept ourselves as we are, with a strong commitment to recover. Do not think about the past*'.

Another participant also had the same way of accepting herself by not remembering the past and focusing on thinking about the future, saying '…*don't think about what you used to be… you have to see the future*'. Another participant added, '…*always introspect yourself… so you can understand about yourself and can rebuild yourself*'. Another participant said the same thing, stating '…*don't despair… be thankful for your life*'. Other participants found various ways of accepting themselves by thinking positively and having the spirit to recover.

Seeking God's Help as a Way to Get Well
This theme was approved by almost all participants (six participants) at the FGD. The survivors have almost the same way of recovering by seeking God's help. A participant shared how to be healed by always remembering God, stating '…*remember God continuously… pray to him*'. Another participant agreed and said that his healing was achieved by seeking the help of Allah and by always loving Allah, stating '…*love for Allah… so he will love you*'. Other participants have the same way of recovering, i.e., by participating in Islamic studies, along with the statement, '…*join the recitation… and… studying religion*'. From the statement of the participants above, it can be seen that the survivors' spiritual responses are shown by their effort of seeking God's help to heal in a variety of ways and prioritising God in every healing process.

Ignoring by the Government
This theme was approved by five participants. In this theme, the participants proposed various responses on how the government should support the recovery process. A participant stated, '…*we want support and attention from the government*'. The participant's opinion was supported by another participant who reminded the government not to

underestimate people with mental illness, saying '*…the government should not look at us with one eye*'. Another participant also agreed to his friend's statement and stated that the government should not ignore people who have mental disorders, saying '*…the government should not ignore us*'. Another participant also had the same hope for the government, suggesting that there should be many recovery-based programmes for mental illnesses, saying '*…there must be many programmes from the government for us*'. From the statements above, it can be seen that survivors have great hopes for the government to provide recovery-based community mental health services to support the healing process.

Discussion

Theme 1: Becoming an Agent of Recovery

In this study, almost all participants revealed that healing is the responsibility of the individuals themselves. A survivor is an agent of recovery, which means that the survivor should become the central point and should participate majorly in the recovery process. Recovery puts the individual as the agent of his/her own story, rather than as the recipient of clinical care (Woods et al., 2022). In this study, all participants confirmed that recovering from an illness is an individual's responsibility. This means that every survivor is responsible for his or her own recovery.

Through a long experience (10–15 years) participants finally found that he/she was responsible for his/her recovery. Even though they have a mental disorder they must be responsible for themselves. In Indonesian culture, a child will feel ashamed if he continues to depend on his/her parents. A child should take care of his parents when his parents are getting older, rather than burdening them. These findings supported those of Hancock et al. (2018) that, in the recovery process, which sometimes goes up and sometimes down, it is the survivors who are responsible for the process so that the sustainability of the recovery can be maintained.

Unfortunately, mental health services in Indonesia today are still medically-oriented, which places doctors as determinants of patient treatment (Suryani Suryani et al., 2013). Patients must adhere to whatever the doctor says, and other professionals also have little influence in treating patients. Everything is determined by the doctor. This situation will certainly affect the recovery process of survivors. Doctor-centred health services result in patients becoming dependent and, of course, never being able to fully recover.

Based on the description above, it is crucial to change the concept of providing services in Indonesia, from a medical-centred to person-centred orientation. Survivors should become the centre of their recovery. They are the origin of power or strength from within that drives, evokes, moves and controls them to achieve their recovery, which enables them to live productively.

Theme 2: Keeping a Smile in All Situations

Matsumoto and Juang (2016) proposed that emotion refers to a typical feeling and state of mind that prepare an individual to do something. New evidence suggests that positive emotions, particularly gratitude, may also play a role in motivating individuals to engage in positive behaviours leading to self-improvement. We propose and offer supportive evidence that expressing gratitude leads people to muster effort to improve themselves via increases in connectedness, elevation, humility, gratitude, happiness, positive emotions, self-improvement, and wellbeing. According to Armenta, Fritz, and Lyubomirsky (2017), positive emotions can encourage someone to behave positively so that they can improve their physical, mental and social health.

In this theme, the positive emotion that emerges is a smile that can provide happiness and healing. This statement was expressed by one participant who revealed that healing can be obtained happily by yourself and others with a smile. She stated, '*…A smile can heal illnesses. You feel happy when you see someone smile to you, and we should be able to smile in every situation, be happy*'.

Although not all participants expressed this feeling, the researchers considered this theme as important, as it is a new insight into this research because there were no previous studies that found and reported it. Moreover, keeping a smile is one of the characteristics of Indonesian people, especially the Sundanese people, who always promote 'welas asih' (compassion for others). The 'welas asih' has been the spirit of the Sundanese people's everyday lives.

Smiling when dealing with various conditions that occur in life is a part of the religious teachings in Indonesia. Facing problems with a smile indicates that individuals are patient and sincere in dealing with them. This is in line with the results of Fauziah, Suryani, and Hernawaty (2019) in which one of the themes found that families are patient and sincere in dealing with the stigma of mental disorders in the community against sufferers.

Theme 3: Accepting Yourself as You Are

In this theme, almost all participants revealed that '*accepting yourself as you are'* is very important in the recovery process. Self-acceptance is very influential on how a person goes through life. If people can accept themselves, then they will not be afraid to see themselves honestly, because they cannot run away from themselves, no matter what they do. According to Bernard, Vernon, Terjesen, and Kurasaki (2013), self-acceptance as a positive character has been proposed in positive psychology as a strong character that is related to happiness and wellbeing.

Accepting yourself as you are is an important element of the recovery process as expressed by

participants in this study and is the attitude taught by parents to their children since childhood. This attitude comes from Indonesian culture, which is rooted in Islamic teachings, stating that humans must be able to accept whatever happens in their lives as God's destiny (provision). This concept was also found in a previous study conducted by Rahmawati, Suryani, and Rafiyah (2017) in West Java, Indonesia, where one of the themes suggested the importance of self-acceptance in order to be motivated to recover. Similarly, Subandi (2015) in Central Java, also found the importance of self-acceptance to "Bangkit" (an Indonesian word meaning motivational force that can exert a transformative effect on individuals faced with illness and seeking to recover) as an important theme in his study. Participants can "bangkit" from their condition or illness if they are able to accept themselves

Theme 4: Seeking God's Help as a Way to Get Well

In this study, all participants revealed that they sought help from God to overcome the pain. This theme was important for participants to raise, and it gives new insights for health professionals. In this study, one of the participants revealed that '… Tahajjud prayers and reading Quran can help my healing process'.

They seek help from God because they believe that God is the most powerful and merciful, and only by seeking help from him can people be protected from evil spirits. At times of seeking help from God, participants turned to Tahajjud prayers and reciting the Quran as a means of invoking Allah's help. Tahajjud prayer is a special Islamic prayer, which is recommended (but not compulsory) for all Muslims. The Tahajjud is prayed after Isha (the obligatory nightly prayer) and before Fajr (the obligatory morning prayer).

This finding is supported by a previous research conducted by Suryani (2013b) concerning the 'Experience of Indonesian Muslim with Chronic Mental Illness'. The study emphasised that spiritual approaches, such as prayers and dhikr, can help individuals with mental illnesses prevent the emergence of voices. Participants in both studies revealed that only God can help them. Therefore, they are very eager to seek God's help, through ritual activities of worship and prayer. This is the characteristic of Indonesian religious people who believe in the power of God above all else

In Eastern countries, religious beliefs have been proven to support recovery (Dein, 2017; Subandi, 2015; S Suryani, 2013). However, according to Okasha et al. (2012), religious and spiritual beliefs are powerful forces and may impart both harmful and beneficial effects; therefore, a tactful consideration of patients' religious beliefs and spirituality should be considered as an essential component of psychiatric history. An understanding of religion and spirituality and their relationship to the diagnosis, aetiology and treatment of psychiatric disorders should be considered as essential components of both psychiatric training and continuing professional development.

Mental health nurses and other mental health professionals are expected to respect and be sensitive to the spiritual/religious beliefs and practices of their patients and the families and carers of their patients (Ho et al., 2016). Whatever their personal beliefs are, mental health professionals should be willing to work with leaders or members of faith communities, in support of the wellbeing of their patients (Ho et al., 2016), and should encourage all colleagues in mental health work to do likewise. Mental health nurses should, whenever appropriate, work to better understand colleagues and patients of different religions and cultures, bearing in mind that social harmony contributes to mental health and wellbeing.

Theme 5: Ignoring by the Government

Almost all participants in this study perceived that the government ignored them. The results of this study are consistent with what we found during community mental health programmes in the working area of the Melong Health Centre where this study was conducted. We found that there were still many people with mental illnesses who did not receive treatment and visits from the community health centre. Mental health services are only oriented inside the building. Home visits, counselling and health education do not work effectively. In addition, there are no governmental programmes that deal with the stigma in the community, and no mental health programmes are related to recovery.

Unlike mental health services in Indonesia, recovery services oriented for people with mental illnesses in developed countries, such as America, England, Australia and New Zealand, were developed many years ago (Boardman & Shepherd, 2012), for example, the Centre for Psychiatric Rehabilitation in Boston University, USA. This centre promotes wellness, resilience and recovery services that are supported by the government, community and University. In England, the recovery-oriented programme for mental health has been established since 2011 by the Department of Health through The Implementing Recovery – Organisational Change (ImROC) project that was funded by government. In Australia, not only has this recovery programme been developed, even a national framework has been created by the Queensland Mental Health Commission. The purpose of the framework is to support the development and expansion of lived experience roles across Queensland (Byrne et al., 2015).

Unfortunately, the situation of people with mental illnesses in Indonesia is still far from satisfactory. They do not receive the appropriate treatments necessary for recovery. Some of them even have no access to treatment as services for mental illnesses are not available in some areas in Indonesia. Primary health services do not have mental health as a

priority, and the skills of primary health clinicians are not sufficient to ensure detection and appropriate treatment of mental disorders. Some people with mental illnesses are confined and restrained in the community, and custodial treatments dominate in psychiatric hospitals. As in many developing countries, the standards of care of mental health services in Indonesia are still poor.

The finding of this theme can become basic information for the Indonesian government to pay more attention to mental health problems and develop programmes that can support the recovery process of people with schizophrenia. The Indonesian government should put mental health programmes as a priority in community health centres. The government needs to make mental health an important programme at the puskesmas, as with the six other main programmes, and increase funding for its implementation.

Conclusion

During the process of recovery, the Indonesian survivors confirmed that they have become agents of their recovery. They developed their way to recover by accepting themselves, keeping a smile in all situations and seeking God's help to get well. In the process of recovery, schizophrenia survivors need support from the family, environment and policymakers. Moreover, the survivors are the centre of the recovery process, so patient-centred care is implemented when providing nursing care.

Declaration of Interest
The authors declare no conflict of interest

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