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THE REINTEGRATION PROCESS OF PEOPLE WITH SCHIZOPHRENIA WHO REPEATED RELAPSE RETURN INTO THE COMMUNITY

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Abstract. *The reintegration of people with schizophrenia to return to society often has to experience obstacles due to repeated relapses caused by multiple factors such as non-adherence to medication or certain social pressures that trigger the emergence of schizophrenia symptoms. The implications of recurrence are closely related to the decrease in the ability to carry out social functions, so they have the potential to lose their jobs, cannot continue their education, and have estranged social relations. There is a phenomenon that several people with schizophrenia who have had recurrent experiences can reintegrate into their social environment. Therefore, this study aims to describe the process of reintegration of people with schizophrenia who experience repeated relapses into society. The research method used is qualitative, with a case study approach on four people with schizophrenia living in four locations in Jakarta. The results of this study indicate that the two elements are operational and interrelated with each other. First, the main element is the individualistic internal process of people with schizophrenia which includes aspects of spirituality, cognition, and mental and social. Second, the enabling element, namely friends/friends and family who work to increase the chances of people with schizophrenia regaining self-stability to reintegrate into their social environment. Success in the social reintegration process allows people with schizophrenia to carry out their social functions as members of society, such as working, having a family, interacting naturally, and overcoming the fear of stigma and discrimination.*

Keywords: *Relapse, Reintegration, People with Schizophrenia.*

Abstrak. Reintegrasi orang dengan skizofrenia untuk kembali ke masyarakat seringkali harus mengalami hambatan akibat kekambuhan berulang yang disebabkan oleh multifaktor seperti ketidakpatuhan minum obat atau tekanan sosial tertentu sehingga memicu munculnya gejala skizofrenia. Implikasi kekambuhan sangat erat kaitannya dengan penurunan kemampuan melaksanakan fungsi sosialnya sehingga berpotensi kehilangan pekerjaan, tidak dapat melanjutkan sekolah, dan kerenggangan hubungan sosial. Terdapat fenomena sejumlah orang dengan skizofrenia yang memiliki pengalaman kambuhan, ternyata mampu terintegrasi kembali dengan lingkungan sosialnya. Oleh karena itu, penelitian ini bertujuan untuk mendeskripsikan tentang proses reintegrasi orang dengan skizofrenia yang mengalami kekambuhan berulang ke masyarakat. Metode penelitian yang dipergunakan adalah kualitatif dengan pendekatan studi kasus pada empat orang dengan skizofrenia yang berdomisili di empat lokasi berbeda di Jakarta. Hasil penelitian ini menyatakan bahwa terdapat dua elemen yang beroperasional serta saling berkaitan satu sama lain. Pertama, elemen utama yaitu proses internal orang dengan skizofrenia yang bersifat individualistik yang meliputi aspek spiritualitas, kognisi dan mental, serta sosial. Kedua, elemen pemungkin yaitu teman/sahabat dan keluarga yang bekerja untuk memperbesar peluang orang dengan skizofrenia meraih kembali stabilitas diri agar mampu terintegrasi kembali dengan lingkungan sosialnya. Keberhasilan dalam proses reintegrasi sosial memungkinkan orang dengan skizofrenia mampu melaksanakan kembali fungsi sosialnya sebagai anggota masyarakat seperti bekerja, berkeluarga, berinteraksi secara wajar dan mampu mengatasi ketakutan stigma dan diskriminasi.

Kata kunci: Kekambuhan, Reintegrasi, Orang Dengan Skizofrenia.

INTRODUCTION

Schizophrenia is a severe medical mental disorder characterized by the poor individual ability to judge reality due to hyperactivity of the hormone dopamine so that the brain sends distorted information due to decreased ability to filter information. Characteristics of people with schizophrenia are experiencing positive symptoms (hallucinations and delusions), negative symptoms (flat effect, anhedonia, withdrawal), and cognitive impairment (Stepnicki, et al., 2018). To this day, a holistic approach that combines medical, psychological, and social is believed to be effective in helping individuals recover from schizophrenia. Medical therapy is placed first to reduce positive and negative symptoms by using antipsychotic drugs regularly (Farah, 2018).

One issue closely related to schizophrenia is the incidence of recurrent relapse, defined as the reappearance of positive and negative symptoms that require individuals to undergo hospitalization for a certain period (Almond, et. al., 2004). Several factors triggering relapse in people with schizophrenia are, first, the role of the family as a caregiver. The low quality of family life due to feeling burdened, stressed, and strained relations are the dominant factors, in addition to the level of education and knowledge (Farkhah, et. al., 2017; Mamnuah, 2021). Second, they have low adherence to taking antipsychotic drugs because they do not comply with the rules of taking medication that a psychiatrist has set. This non-compliance is generally triggered by the stresses of life (Singh, et. al., 2019) and a sense of saturation due to taking antipsychotic drugs for life (Olivares, et. al., 2013). The third is the short duration of following the treatment. Fourth, the lives of schizophrenic people are full of stress (Moges, et. al., 2021; Wang, et.al., 2021). Lastly, the severity of the mental disorder itself also increases the risk of recurrence (Larry, et. al., 2016). The logical implication of recurrent relapse in people with schizophrenia is the occurrence of functional and social disabilities such as being expelled from school, losing a job, unable to live independently, losing friendships, increasing the risk of suicide, neglect, depression, and loss of hope (Nasrallah, 2021).

Discussions related to recurrent relapse in people with schizophrenia are generally more directed to two things. Firstly, identifying the factors that influence it, such as stressful, emotional, and non-adherence to treatment (Haque, et. al., 2017) and supportive factors. family (Rokayah & Rima, 2020). Secondly, the development of relapse prevention intervention strategies. The strategies include early detection, collaborating with families and other sources of support, being flexible and having access to health services, optimizing pharmacological therapy, ensuring adherence, and being sensitive to symptoms of recurrence (Lamberti, 2001). The main focus of this research is on the reintegration of people with schizophrenia who experience recurrent relapses back into society. According to the International Organization for Migration (IOM, 2019), social reintegration is a process that allows individuals to regain economic independence, social and psychosocial relationships needed for life, livelihood, self-esteem, and inclusiveness in society. Some important elements also considered are support from social networks and the ability to live in the face of stigma and discrimination (Dale-Perera, 2017). Based on the social distance between the community and people with schizophrenia, stigma and discrimination (Haraguchi, et. al., 2009), the significance of this study is a form of exclusivity as a source of stress.

Based on the abovementioned problems, this study aims to describe the reintegration process of people with schizophrenia who experience repeated relapses back into society. This study is expected to contribute to scientific facts about the elements working in the reintegration process to be implemented in helping people with schizophrenia in the family.

METHOD

This study uses a case study qualitative research method to obtain information related to the similarities or differences of each case. First, the data collection technique uses semi-structured in-depth interviews (Newman, 2017). Second, non-participant observation. The participant selection technique using purposive sampling with inclusive criteria is that they are over 18 years old, have had schizophrenia for more than five years, have had repeated relapses, and have been able to function socially again (work, interact, get married, go to school). Based on these criteria, four participants were selected, namely A, B, C, and D. The research locations were determined according to the domicile of each case, namely in Cilandak, South Jakarta, Cibubur, East Jakarta, Plumping, North Jakarta, and Matraman, Central Jakarta. The data analysis technique uses open, axial, and selective coding. To improve the research quality, the researcher uses size and theoretical triangulation techniques (Newman, 2017).

RESULT AND DISCUSSION

Based on the results of data collection obtained through in-depth interviews and non-participant observations, the following is presented

regarding the data of research participants as follows:

Participant A

At the time of the interview, participant A was 44 years old, male, married, and had two children from his marriage. He was diagnosed with schizophrenia in the second grade of high school (SMA) in 1993, which was characterized by symptoms of anxiety, hallucinations, and delusions. Four sudden behavioural changes are experienced by participant A: 1) leaving the house suddenly with only the bag that he usually brings for school; 2) getting around Jakarta using public transportation and moving around without a clear destination; 3) throwing stones at every vehicle that passes on the road until finally they are arrested by residents for considered disturbing the safety of vehicle users, and 4) turning over to the police station. The police checked participant A's bag and found a book with participant A's school name. Based on this information, the police informed the school, so the school and their parents took them to the police station.

Repeated Relapse

The parents immediately decided to take participant A to a well-known private hospital in Jakarta. In the first week of treatment, the positive symptom experienced by participant A was that he still had great delusions that he believed himself to be an important person and was carrying out state duties. In addition, participant A also had visual hallucinations by seeing people who had died, rose from the grave, and returned to life. After about three weeks of treatment, participant A was finally stable again due to the intervention of antipsychotic drugs he regularly took. The hospital also allowed him to go home with a record that he regularly took medication and had regular check-ups with the doctor.

Based on the results of the interview, it is known that several incidents caused recurrence in participant A: 1) non-adherence to medication for he felt that he had recovered and no need to continue treatment; 2) when his biological mother passed away, it caused anxiety that affected the increase of the dose of the drug; 3) when his biological father passed away two years after his biological mother passed away; 4) when his wife was about to give birth to her first child.

Participant A was slightly depressed because he doubted his ability to become a father. Reactions to behaviour change when experiencing a relapse are tantrums in the office by cursing at superiors, tantrums outside the house while standing on the roof of a neighbour's car, and going on a motorbike without a clear purpose.

Reintegration Process

According to participant A, shame is a natural thing experienced by people with schizophrenia because when it is relapsed and witnessed by others, it must always be a topic of discussion among these people. Some important things related to the reintegration process are spiritually believing that every human being created by God has weaknesses, and the weakness of participant A is schizophrenia. Psychologically accept schizophrenia as part of his distinctive personality and make schizophrenia a tool to help others. This acceptance includes choosing to ignore other people's negative views of him. Participant A chooses to focus on the happiness of himself and his family.

Socially, participant A keeps trying to work even though he has been transferred to a section that is less pleasing to him because he feels excluded; he remains open to social interaction with neighbours, for example, by playing chess, joining the community with fellow individuals with schizophrenia, and being active in the church. Based on the observations, there was no distance between participant A and the community. Participant A and his neighbours met when they passed by or passed by in front of his house. Some neighbours who like to raise roosters also stopped by the house of participant A who has a similar hobby. He can talk about chickens for about an hour. Participant A concluded that one of their strengths in him so that he can be reintegrated is not feeling sorry for himself excessively. People with schizophrenia have to fight for their own lives. Participant A also emphasized the importance of the wife's role in helping participant A to stay active outside the home when there is free time or a day off from work.

Participant B

Participant B's background is a woman who has had schizophrenia since ten years ago. Participant B is an alumnus of a private university in West Java and is currently working in a private company in Jakarta. According to participant B, since high school, he has behaved differently than his classmates because he tends to be quiet, so he often experiences bullying. This unpleasant experience caused him to continue his education at a campus far from his hometown in Jakarta to minimize the possibility of meeting his high school classmates. During the lecture, participant B began to experience

voice hallucinations that cursed him with harsh words such as prostitutes, useless people, and orders to commit suicide. Therefore, participant B mostly closed himself in his boarding room and only left his room to eat, to the bathroom, and campus. He had a suicidal urge because he could not continue to hear voices every day for 24 hours. Participant B finally tried to consult a psychiatrist and found that he had a schizophrenic disorder.

Repeated Relapse

Participant B has never been hospitalized due to schizophrenia. The treatment process is followed by regular check-ups with the doctor every month. It is admitted that participant B sometimes feels bored because they have to take antipsychotic drugs every day, even though the drugs help stabilize the disorder for him to finish college and work. Participant B has used the BPJS facility every time he controls and takes medicine at the hospital. It is recognized that participant B is very helpful to him. The inconsistency in the consumption of antipsychotic drugs also cannot be separated from the role of parents who are worried about the long-term effects of chemical drugs on the organs of participant B and believe that participant B does not suffer from schizophrenia at all but because of witchcraft. Therefore, the family took participant B to a psychic who was considered capable of curing participant B.

The inconsistency of medication caused participant B to experience depression symptoms again, experience sleep disturbances, or hear voices again. Over time, the schizophrenic disorder got stronger. It began to appear in behavioural changes as follows. First, participant B was angry at the office because he believed himself to be being scolded by one of his colleagues, so a dispute arose because he immediately accused one of his friends. Second, participant B is often angry because his emotional condition is unstable. Third, the leadership often reprimands participant B because he often comes late due to a sleep disorder. Fourth, social relations with friends in the same company are tenuous. In the end, the company finally chose not to extend the work contract of participant B.

Reintegration Process

Repeated relapses finally made participant B aware that he must have a good relationship with antipsychotic drugs and accept schizophrenia as something inside him that cannot be eliminated. The most rational choice is to accept it so that his mental state does not constantly conflict with his desire to be the same as other people living without schizophrenia. The next decision taken by participant B was to firmly refuse to participate in paranormal healing because it was not useful at all and burdened him more and more; besides, the costs incurred were also quite large.

In the next step, participant B attempted to reconcile by contacting his social relations, which he assessed had been harmed when participant B had a relapse. Openly, participant B apologized and explained his condition openly his true condition. According to Participant B, it is natural for his colleagues to view him negatively, even stigmatizing him, because this stems from ignorance. That is the basis for opening up and apologizing. In the end, this openness encouraged some of his friends to find out more and asked participant B to explain in detail. Based on observations, participant B was able to restore his social relations and kept in touch with his old office mates after getting a new job. Participant B emphasized the importance of having the courage to start over from scratch. In addition, according to participant B, the family always includes him when there are family and social events around his house as a form of support so that participant B can return to his community.

Participant C

Participant C is a 36-year-old male, married, works in a service company, and has been living with schizophrenia for about 17 years. Schizophrenia disorder experienced by participant C is an accumulation of the behaviour of participant C, who used drugs in the long term while still in high school. Initial symptoms in the form of hearing orders to kill and suicide began to be experienced during the first year of college. His condition is worsening because he adds delusions that believe he is a messenger of God tasked with punishing humans for many sins. Participant C's emotions are also unstable because they are easily angry with others for no apparent reason.

Repeated Relapse

At first, the family of participant C considered that the behaviour change experienced by participant C resulted from the actions of people who did not like it, so they sent witchcraft. The family then brought participant C for therapy with a psychic to be cured. After switching to psychic several times, and showing no results in the direction of change, finally, the family took participant C for treatment at a private hospital. Based on the doctor's examination results, the family discovered that participant C had a schizophrenic disorder. The doctor then asked the family to accompany participant C to regularly take medicine and consult a doctor according to a predetermined schedule.

After hospitalization, participant C's condition returned to normal as before. Compliance with medication was quite good until participant C finally completed his education at his campus. The relapse started when participant C was already working and assessed that his body condition was improving, so there was no need to continue taking medication and see a doctor for control. On personal initiative, participant C stopped taking antipsychotic drugs. Several months later, the symptoms of schizophrenia began to reappear. Participant C started to get angry for no reason at the office. Finally, the office asked participant C to rest at home for a while. However, participant C's condition worsened because his hallucinations and delusions were getting stronger. Participant C closed himself in his room alone because he was afraid. The family also responded to this change by bringing participant C back to the hospital for hospitalization. After three weeks of treatment, participant C's condition stabilized, and he was allowed to go home.

Furthermore, participant C was accepted to work in a new company in the field of sales because participant C was embarrassed to return to the old company. However, participant C again experienced a relapse due to drug withdrawal, so he was dismissed from his company. Participant C explained that this had happened several times and forced him to change jobs.

Reintegration Process

Entering 30 years, participant C reflected that he should not continue in the recurrence cycle. The results of the contemplation made participant C aware that he needed antipsychotic drugs if he wanted to maintain his stability. Mentally, participant C is ready to face the consequences of being a person with schizophrenia, and it is destined to be so that it cannot be changed again. His main focus right now was just to keep himself stable. Participant C felt lucky because his friends during college continued to support him and always invited him to go futsal together, gather at the cafe, or his friends visit his house. This support is very important for participant C because he openly admits that the repeated recurrences cause him to feel inferior and ashamed. The thing that is worried about by participant C is the stigma from the community, who think he is insane. The family is also very supportive and accepts the presence of participant C's friends, who are always willing to accompany and support participant C so they can finally carry out their activities as usual. Participant C became less easily offended when his friend jokingly reminded him of the drug.

Participant D

Participant D is male, 30 years old. The first time he experienced symptoms of schizophrenia was after graduating from high school (STM) in Jakarta in 2010. At that time, participant D felt he saw scary creatures with fangs, black colour, and changing shapes. In addition, participant D also started talking and laughing alone at home. In fact, according to family information, participant D seemed to be playing with an invisible figure. Sometimes, wearing neat clothes and walking alone without a clear purpose. The family is very worried about the change in the behaviour of participant C but does not know how to help him. The family only took participant C to local spiritual figures for prayer because they suspected an evil spirit possessed the participant.

Repeated Relapse

In fact, on the advice of a local spiritual leader, the family also decided to take participant D to the hospital. When he was brought in, the condition of participant D was already delusional as a famous rock musician. The participant underwent treatment in a hospital psychiatric ward for about three weeks and took antipsychotic drugs regularly. According to participant D, the problems of people with schizophrenia at the beginning of treatment were generally the same. If they feel healthy, they tend not to continue taking medication because people with schizophrenia believe their disease is the same as other diseases. If he has been allowed to go home from the hospital, it will be a sign that he has recovered.

For approximately one year after being treated, participant D was stable. However, the drugs have not been taken for the last four months. Indeed, participant D can still carry out his usual activities at home or occasionally help with the work of a neighbour who needs his help to repair the house. Gradually, participant D began to experience hallucinations and delusions again. Voices began to sound again, strange shapes reappeared, and he felt like a very handsome famous character. The family finally decided to take participant D to the hospital for hospitalization. The second relapse occurred when participant D had worked in a factory in West Java, so participant D had to be brought back to his parent's house in Jakarta by several of his co-workers. The third and fourth recurrences occurred in Jakarta when participant D worked to help a relative's business.

Reintegration Process

Participant D admitted that he felt tired and embarrassed by his repeated relapses. He feels this relapse is the main obstacle for him to interact with the environment and develop so that he often cannot keep his job. It was this awareness that started the change in participant D's life. According to participant D, this characteristic of schizophrenia did require him to take medication regularly. Participant D builds confidence that the antipsychotic drug must be safe and useful for him. Since then, participant D has maintained its stability in the long term. Indeed, sometimes participant D still hears neighbours calling him crazy and weird. However, participant D has not thought about this. So far, his friends and closest family have always supported him in returning to normal activities. Therefore, participant D focuses more on self-comfort because no one does not have flaws in his life. It was also added that as a person with schizophrenia if you want to be accepted back into the community, you must take the initiative to practice getting out of the house by sitting on the terrace of the house, walking out around the house, taking public transportation, drinking coffee at the shop, and other simple things.

DISCUSSION

Relapses experienced by people with schizophrenia are multifactorial such as ignorance about the disorder's characteristics, feeling bored taking medication, feeling healed, or being triggered by family events that affect their emotions, such as the loss of a parent who is very important in their lives. The repeated relapses have implications for the decreased ability of people with schizophrenia to control their emotions and carry out their social functions. It impacts the stretching of social relationships, the cessation of the educational process, and being unable to maintain the job they already have. Psychologically, these relapses also make people with schizophrenia feel ashamed, have low self-esteem, and feel guilty because of the behaviour resulting from being influenced by schizophrenia. Problems also develop because people with schizophrenia become worried about society's stigma, which they see themselves when they are experiencing a relapse. This stigma influences them to choose a distance to avoid the possibility of getting unpleasant treatment due to negative stigma.

Referring to the main focus of this research, reintegration of people with schizophrenia with relapse experiences back into society can be possible if it fulfills two elements, namely the main elements and interrelated enabling elements. The main element is the individual process itself. People with schizophrenia are the main actors in the reintegration process because they must consciously make efforts to make fundamental changes within themselves in order to be able to get out of the relapse cycle. There are three elements in the individual life that must be changed: spirituality, cognitive and mental, and social. The spirituality element here means a belief that schizophrenia is the will of God, who created humans with all their strengths and weaknesses. The cognitive and mental elements here means accepting themselves as they are, not feeling sorry for themselves, focusing on life, daring to face stigma, and making peace with schizophrenia. The social is restoring social relations, for example, by apologizing to people in the closest social environment due to misunderstandings when experiencing a relapse. These changes show that people with schizophrenia can manage and regulate their emotions as an important part of supporting the implementation of their social functions (Kimhy, et al., 2012).

Another thing is to train yourself to re-enter the social environment by doing activities outside the home. The enabling elements, in this case, are friends/friends and family who operate in different ways. Friends/friends are more proactive in approaching people with schizophrenia from the outside to put them back into social interaction, so they do not just lock themselves in the house. The forms of home visits or inviting him out of the house to be in the social environment are very helpful in the process of social reintegration. In comparison, the family works to involve people with schizophrenia in the social environment through family activities. This enabling element acts as a co-therapist (Dwizota, et al., 2017) and social support (SabryEbrahimAbdElmonem, et al., 2021) in order to facilitate people with schizophrenia to practice social skills in order to improve the ability of people with schizophrenia to socialize and carry out their social functions (Kotijah & Munfadlila, 2019).

The main and enabling elements are interrelated to make it easier for people with schizophrenia to reintegrate into their social environment to get the opportunity to carry out their social functions and realize independent life. Support from enabling elements plays a big role in reviving the energy of people with schizophrenia who are at a low point after experiencing a relapse, thereby reducing their cognitive, emotional, and social abilities. The role of this enabling element is very strategic as an effort to prevent the occurrence of social disability, which will affect the ability of social interaction, concentration, perception, interpretation, attention, and motivation in the long term (Green, et al., 2018). The process of change in

people with schizophrenia must be admitted as the main element is very individualistic. Therefore, the collaboration between the main and enabling elements has the potential to increase the chances of people with schizophrenia finding a supportive self-inspection towards self-recovery (Soroka, et al., 2017) as a turning point in their lives by interpreting all the processes they have experienced so that they can reconstruct them. The main elements in him to change, such as spirituality, cognitive and emotional, and social, become a force to determine the direction of life, form relationships with schizophrenia, and courage to face societal stigma against people with schizophrenia.

The concrete form of determining the direction of a new life is the courage of people with schizophrenia in making decisions that can be known at least from two things, first, related to antipsychotic drugs, which have been seen as a need to maintain body stability. This need indicates the readiness of people with schizophrenia to cope with boredom caused by taking medication for the long term; second, the initiative to enter the social environment to eliminate social distance due to stigma between schizophrenic people and their community. People with schizophrenia dare to face the possibility of getting unpleasant treatment and getting rid of negative prejudices against society to regain the best possibilities in life. They realize that isolating themselves is no longer seen as the best option. In the end, people with schizophrenia can reintegrate into their social environment so that their social functions, such as working, continuing education, maintaining the household, interacting with other people, and obeying social rules, can be achieved again. This achievement indicates that people with schizophrenia have mastered the executive function (EF), which plays a role in controlling their behaviour to make plans, make analogies, obey social rules, solve problems, deal with unexpected environmental situations, carry out several tasks, be able to concentrate, and have goals. (Orellana & Slachevsky, 2013).

CONCLUSION

The process of social reintegration of people with schizophrenia with repeated relapse experiences is influenced by two elements, namely the main element, the person with schizophrenia itself, and the possible element, in this case, is the closest social environment, namely family and friends/friends. Enabling elements create a conducive space for the main elements to interpret their relationship with schizophrenia, which is associated with spiritual, cognitive, mental, and social aspects. This achievement allows people with schizophrenia to be reintegrated with their community to carry out their social functions such as working, continuing school, having a family, and interacting naturally in their social environment. Based on these findings, it is suggested that to achieve the goal of social reintegration, people with schizophrenia as the main element and their closest social environment (friends/close friends, family).

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