



## Lived Experiences of The Recovery Process of People with Schizophrenia During a Pandemic

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### ABSTRACT

The existence of social restrictions and activities during the pandemic in the last two years may have hampered the recovery process of people with schizophrenia. The Denpasar City Empowered House Rehabilitation Center is designed as a place for people with schizophrenia in the community to recover, become independent, and be productive. Several studies have attempted to explain how people with schizophrenia recover, but little is known about how this happens during pandemics. Therefore, this study used interpretive phenomenological methods to explore and understand the meaning of life for people with schizophrenia. The participants were 5 people with schizophrenia who were at the Denpasar Empowered House. Furthermore, interviews were conducted using in-depth techniques. The interview data were transcribed verbatim and analyzed using the Creswell approach. The results obtained 8 themes, namely: (1) Feeling cared for by others, (2) Accepted by the community, (3) Having a positive self-identity, (4) Ngayah helping the recovery process, (5) More helpful to explore self-ability, (6) To recover, (7) Enjoy active socializing, and (8) Situations that affect self-ability. It can be concluded that the participants interpret the recovery process as a goal to return to being part of the community during a pandemic.

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#### Kata kunci:

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### ABSTRAK

Adanya pembatasan dan aktivitas sosial selama pandemi dalam dua tahun terakhir dapat menghambat proses pemulihan penderita skizofrenia. Pusat Rehabilitasi Rumah Berdaya Kota Denpasar dirancang sebagai wadah bagi penderita skizofrenia di masyarakat untuk pulih, mandiri, dan produktif. Beberapa penelitian telah menjelaskan bagaimana penderita skizofrenia dapat pulih, tetapi sedikit yang diketahui tentang bagaimana proses pemulihan penderita terjadi selama pandemi. Oleh karena itu, penelitian ini menggunakan metode interpretif fenomenologis yang bertujuan untuk menggali dan memahami makna hidup bagi penderita skizofrenia. Partisipan adalah 5 orang penderita skizofrenia yang berada di Rumah Berdaya Denpasar. Selanjutnya, wawancara dilakukan dengan menggunakan teknik wawancara mendalam. Data wawancara ditranskripsikan secara verbatim dan dianalisis menggunakan pendekatan Creswell. Hasil yang diperoleh yaitu sebanyak 8 tema: (1) Merasa diperhatikan oleh orang lain, (2) Diterima oleh masyarakat, (3) Memiliki identitas diri yang positif, (4) Ngayah membantu proses pemulihan, (5) Lebih bermanfaat untuk mengeksplorasi kemampuan diri, (6) Untuk memulihkan diri, (7) Menikmati bersosialisasi secara aktif, dan (8) Situasi yang mempengaruhi kemampuan diri. Kesimpulan penelitian ini adalah penderita skizofrenia dapat memaknai proses pemulihan sebagai tujuan untuk kembali menjadi bagian dari masyarakat selama pandemi.

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## INTRODUCTION

The Corona Virus Disease 2019 (COVID-19) pandemic, which has been ongoing for the past two years, has had a global impact on the emergence of various diseases, including mental health issues, the severity of illness and is predictable to place a strain on the healthcare system (Esposito et al., 2021). The impact of social restrictions and activities also impedes the recovery of people with schizophrenia (PSW) in the community. The recovery process is not limited to increasing knowledge, but also to the promotion of new abilities that are beneficial to their productivity or even symptom reduction so that they can manage their lives independently (Lysaker et al., 2020). The mental health services managed by the community are quite important for improving the recovery process of PSW (Horsfall et al., 2018). The risk of recurrence of schizophrenia is higher when there is a delay in treatment, and when the family does not bring them to the hospital (Jo et al., 2020). The recovery process is influenced by the personal relationship, hopes, optimism, identity, the way of understanding life, and their empowerment in the society (De Mare et al., 2018; Fortune et al., 2015) The debate about recovery process of PSW is still growing where it is a way in which individuals with mental health challenges regain and develop significant relationships with family, friends, community, and themselves, as well as to overcome the effects of harm from stigma (Apostolopoulou et al., 2020). The recovery process still conveys their desire to recover, their needs, hopes, and aims regarding what therapy can or cannot be used (Vanteemar S. Sreeraj et al., 2019).

The recovery process in people with this disease is considered important because the concept of recovery described in the CHIME framework has components of Connectedness, Hope and optimism towards the future, Identity, Meaning in life, and Empowerment. This concept explains that environmental factors that benefit individuals such as strong social support, good personal abilities, and less susceptibility to biological factors buffer against the deleterious effects of stress. Furthermore, the factors promote a better prognosis and find a significant reduction during the nine months of therapy (Li et al., 2018; Lim et al., 2017). The CHIME is a concept that describes an individual's recovery process, and it involves five processes, namely connectedness to others, hope and confidence in the self-recovery process (hope and optimism), self-confidence, having a positive self-identity, and living a meaningful life (Narussan & Wilken, 2019).

Rehabilitation programs are used to restore the rights and functions of PSW. They improve social skills in the family and the community as well (Chaudhari et al., 2018; Özdemir et al., 2017). Therefore, the Social Service and Denpasar City Health Office collaborated with the Indonesian Schizophrenia Care Community, Simpul Bali, and the Art Ketemu Project Organization to establish the Denpasar Empowered House in 2016. The Denpasar City Empowered House Rehabilitation Center is designed as a place for people with schizophrenia in the community to recover, become independent, and be productive. In this place, recovery services and the equipment are available to socialize PSW. Hence, they can recover, be independent, productive, and create a mentally healthy environment. At the Empowered House, PSW were given skills training (making incense, painting, making coconut oil and prayer tools from newspapers, designing clothes, as well as washing motorbikes) in preparation for entering the community. Also,

they are assisted by psychiatrists, psychologists, nurses, and volunteers with the leading sectors being the Social Service and the Denpasar City Health Office. It is hoped that they can increase positive growth through increasing abilities, relating to others, improving better functional abilities, personal strengths, spiritual changes, and appreciating their lives (Smith et al., 2016). Those who were given psychosocial therapy and drugs showed a higher recovery ability than those given only medication (Chen et al., 2020). Furthermore, those who have attended therapy at Empowered House can interact in the community and are not dependent on their families considering the skills they have acquired. Several studies have attempted to explain how people with schizophrenia recover, but little is known about how this happens during pandemics. Therefore, this study used interpretive phenomenological methods to explore and understand the meaning of life for people with schizophrenia.

## METHOD

The study design used an interpretive phenomenological method, which is a study to find meaning from experiences of PSW (Hu and Chang, 2017). The participants were 5 people with schizophrenia who underwent mental health therapy at the Empowered House Denpasar City. The inclusion criteria were those with schizophrenia, those recommended by the staffs, and those who have obtained permission from their families or guardians. Furthermore, data were collected after the participants have obtained permission from their families, as well as recommendations from Empowered House officers, accompanied by informed consent. Also, in-depth interviews were conducted for approximately 15 to 30 mins using a voice recorder that was pre-approved. The questions asked from the participants to explore their recovery process at Empowered House were:

- How do you feel when you first entered the Empowered House?
- How do you feel about the support of friends in this Empowered House?
- What do you think about the role of the officers in this Empowered House?
- How do you feel compared to the previous therapy given?
- What developments can you make after following this therapy?
- What challenges did you experience while living in this Empowered House?
- What are your hopes for the existence of this empowered house for yourself?
- Do you feel ready to re-socialize with the surrounding environment after participating in this therapy?
- What do you think about the recovery process at the Empowered House?

There were 5 male participants with an age range between 32-47 years. The 5th participant (P5) already has a permanent job as a contract employee at the Empowered House, while the other 4 participants do not have a permanent job. When there is no new information, data saturation occurs. The data were analyzed using the Creswell model with the first step being interpretation of the interview results in the form of verbatim text. The research

team read all the data for coding which then determines the sub-themes of the data grouping. Furthermore, the obtained sub-themes were grouped to form several themes. In addition, the magnitude was determined by linking the obtained themes. The research team did a credibility test by visiting the Empowered House from the beginning and conducted a preliminary study in October 2020. They started observing and working at the Empowered House for approximately nine months. Also, they triangulated the data by checking and re-validating the participants at the Empowered House.

## RESULTS AND DISCUSSION

This study has nine themes, which are as follows: (1) Feeling cared for by others, (2) Accepted by the community, (3) Having a positive self-identity, (4) Ngayah helping the recovery process, (5) More helpful to explore self-ability, (6) To recover, (7) Enjoy active socializing, and (8) Situations that affect self-ability.

### Theme 1: Feeling cared for by others

The PSW at the Empowered House had a sense of concern for themselves, both from the house staff and fellows who they consider as family. It was shown that the participants felt cared for, including being reminded to take their medicine both by officers and fellows, helping each other in daily activities, having fun, and sharing comfort. The effectiveness of medication or therapy adherence for PSW will be better when there is peers involvement (Clifford et al., 2020). This is in line with Hielscher et al (Hielscher et al., 2019) which stated that care by family members or friends provides an important role as support for people with mental disorders. In the concept of the CHIME framework, caring is included in connectedness where the participant's statement indicates that there is support from the environment, staff, or from fellows. Therefore, the sub-themes of feeling cared for by others include being reminded to take their medicine, helping each other, and making participants feel comfortable during the recovery process.

The first sub-theme includes *being reminded to take their medicine* which is supported by the participant's statement as follows:

*"...Because I used to be a bit naughty, I didn't want to listen, I didn't want to take medicine and maybe he helped me to remind me to take medicine and my friends also reminded me to take medicine..." (P1)*

*"... For psychologist friends like her, she helps and encourage us and sometimes she reminds us to pay attention to taking medicine...just like that..." (P1)*

*"...From my experience at this empowered house, we support each other, remind each other that it is time to take medicine, that we can do many activities here, especially because I am very close to the supervisor, he is the one who always gives me a solution whenever there is a problem that I face..." (P3)*

The second sub-theme is *helping each other*. It has the meaning of helping each other among fellow participants in this empowered house.

*"...So, I can also help and accompany my friends in socializing activities at this empowered house..." (P5)*

*"...The positive sides, we can communicate and share our ideas, with each other..." (P4)*

*"...If it's positive to have more friends, then communication is about exchanging ideas with friends, then exchanging ideas with friends, being given skills at the Empowered House." (P4)*

The third sub-theme is *making participants feel comfortable during the recovery process*. It means providing comfort, and cultivating happiness for participants.

*"...There is an internship student who makes us feel comfortable...because he often checks us and also talks to us, it becomes... comfortable you know..." (P2).*

*"...The volunteers entertain us, make a joke at this empowered house, it's fun to do that..." (P2)*

### Theme 2: Accepted by the community

Being accepted by the community is very important, and PSW expect support during the recovery process. The PSW who do not receive proper care and not involved in social activities will be unable to return to the society (Hung et al., 2021). Also, the participants expressed high hopes of being accepted back by the community by stating they wanted to be treated the same as others and be re-empowered. This was because the longer they did not receive support and were isolated, the gradual the loss of their abilities (Ebrahimi et al., 2018). Therefore, hope and optimism are the recovery process of the CHIME framework related to this theme.

The sub-theme of *being accepted by society*. It means that the participants are being treated and being empowered equally with dignity.

*"...My wish is simple...I probably want to be the same person as everyone..." (P1)*

*"...I live my life in the future. I want it to be calm and don't think about anything else..." (P2)*

*"...Our progress here is assessed and informed to the family, how is my progress while I'm here..." (P3).*

*"...Can blend in with society without being too dependent on other people..." (P5).*

The sub-theme of *being empowered*. It has the meaning of empowering people with skills and activities, so they can take control of their lives. It is found in the participants' statements below:

*"...being able to participate in the activities makes me feel more useful because when compared to staying at home, I probably won't recover like this..." (P1).*

*"...I hope that the government will care more about people with mental disorders like me so that they can develop the creativity of their friends here..." (P3).*

*"...In the future, maybe you have the resources to open a small business, from the skills given in such an empowered house..." (P4)*

*"...learn socialization, learn production skills...so that in the future we become more independent, empowered and able to blend in the society, not relying too much on other people..." (P5).*

### Theme 3: Having a positive self-identity

The participants have the self-identity that they do positively. Also, sub-themes like active participants in the community, believing in their abilities, and exploring their abilities mean they have a positive self-identity undergoing the recovery process at the Denpasar City Empowerment House.

In the sub-term activity, the participants claimed they actively participated in the community. The activities they often participate include working together, youth organizations, or other Banjar activities (village level is the same as community level in Bali). Also, PSW have an unstable moods and behaviors compared to non-schizophrenia (Boulanger et al., 2013). The existence of Empowered House helps them in gaining self-confidence and showing a positive identity. In the concept of the CHIME framework restoration, according to the research team, this theme can be part of the personal identity. The participants claimed that after undergoing the recovery process, they began to respect themselves, developed confidence, and began to think about their future lives. Participants' statements in this sub-theme are:

*"...I am at home...feel empowered, I am more capable of taking responsibility and that means I have dared to face anything..." (P3)*

*"...on Sunday I play with friends, have a conversation like that, continue to join the group of young people..." (P4)*

*"... in general, my social skills activities work well, I can do.....in Bali there are obligations to do the communal work, we called this as ayah-ayahan, I also go to family temple...in that village, I can do everything well..." (P5)*

### Theme 4: Ngayah helping the recovery process

*Ngayah* is a social obligation and is a civic culture in Balinese life in which there is an element of sincerity in doing a job together activities (Utami et al., 2020; Parma & Handayani, 2019). This obligation is carried out by inviting Balinese people from different backgrounds to become one unit full of a sense of brotherhood, sincerity, and togetherness in increasing tolerance (Ayu et al., 2018). The services with life experiences of PSW with a cultural approach are seen as being used to develop psychosocial interventions (Nowak et al., 2017). In this study, the research team revealed that participating in *ngayah* provided an opportunity for the participants to socialize without any stigma obtained from the community. In addition, they feel their mental development is good and it is a fun activity for them because they can interact with residents. Participants' statements regarding this sub-theme are:

*"...In this society, I do not have to feel ashamed, and no stigma towards me and I can do the ngayah activities..." (P2).*

*"...with this ngayah, I can socialize with the community, a place for me to have a conversation with*

*other people again and also know my current condition..." (P3)*

### Theme 5: More helpful to explore self-ability

In the theme of exploring self-ability, participants have the ability to explore what they can do in the recovery process at Empowered House Denpasar (Butler, 2012). A biopsychosocial treatment or therapy model for PSW needs to be applied, including the development of strategies to reverse weakness into improving work outcomes (Wang et al., 2020). Meanwhile, the activity and art therapy are potentials that can be used to help PSW survive with their mental disorders and to improve their life quality and facilitate their recovery. At the stage of the recovery process, this theme entered into empowerment considering that all participants' abilities in continuing their lives were stated in the statement on this theme. In addition, the sub-themes of being able to explore one's abilities include working during the recovery process, exploring self-ability at the beginning, and following continuous therapy. The first sub-theme of *working during the recovery process* implies the active participation of PSW in producing something with their talents. Participants' statements regarding this work theme are:

*"...the therapeutic activities here, filling the emptiness in my life, thinking good thoughts...so I have my initiative, making natural virgin coconut oil here, with friends, about 3 people, and others..." (P3).*

*"...if there is an order from someone to make the clothes, there is a screen printing, and then we start to work..." (P1).*

*"...After I worked at the beginning...I feel empowered, and after that, they appointed me as their employee in this house..." (P5).*

The second sub-theme is *exploring self-abilities at the beginning*. Participants explained that they tried to explore their abilities at the beginning before they carried out an activity. Participants' statements that support this sub-theme are:

*"...When I was homeless, apparently, I just realized from the help of other people that...I was needed, that's where I thought I should be able to change for the better..." (P1).*

*"...I feel changed after praying...I believe in praying like that..." (P2).*

*"...I control myself by thinking first where I want to go after this...where do I want to go..." (P2)*

*Following continuous therapy*, in this sub-theme, means that participants in the recovery process follow therapy sessions regularly and participate in continuous improvement at the empowered house. Participants' statements that support this sub-theme are:

*"...You could say that as time goes by, yes, because I regularly take medication, I feel more stable and can be more productive in the society, so this empowered house is...where I can improve myself to become a better person" (P3)*

*"...Now there is also a motorbike washing activity, making soap...you know, then making incense stick for praying, just like that..." (P4).*

*"...I started the process very early. I usually get tensed when I speak in public. This is a training process at the house..." (P5).*

#### **Theme 6: To recover**

The theme of being recovered in the recovery process is entered into the meaning in life process in the CHIME framework concept. Having a mental disorder has a significant effect on social relationships, learning outcomes, homework, and self-care (Harris et al., 2015). The functional recovery of PSW can be influenced by several factors including a combination of environmental factors, stressful life events, substance abuse, socioeconomic conditions, and family dynamics (Lahera et al., 2018). The research team showed the recovery process had an impact on participants such as making them more self-aware, a place to learn to control emotions, socialize, and the availability of friends to confide in. Healing is closely related to removing the stigma provided by PSW in the community. This is in line with (Singla et al., 2020) which showed stigma plays an important role in determining the recovery of PSW. The sub-themes obtained include to get better and learn self-control. *Getting better*; in this subtheme, the participants hope they will be better off in their level of health than before until they are in the pre-schizophrenic stage. Participants' statements that support this sub-theme are:

*"...I can make people who were never aware of themselves...then they become more self-aware...to be able to develop and rise for the spirit of life to come, or...what I can say is that they can recover, stabilize or can be said...to be recovered to work, that's all..." (P1)*

*"...Here I learned how to recognize myself...because I was dealing with people here as well as people who were in the same case like me, I am more grateful, more grateful, more introspective..." (P3)*

The sub-theme of *learning to control themselves* means the participants by undergoing the recovery process taught how to control themselves both in words and behavior on an ongoing basis. Hence, the participants can control themselves well. Participants' statements that support this sub-theme are contained in the statements below:

*"...a person with a mental disorder you knows... they are emotionally unstable. Here I learned how to manage that emotion so that it doesn't explode like before..." (P3).*

*"...a place to share our experiences...like that, for example, there is a friend who is upset and depressed in his family, at this house...maybe he can tell his story, and singing songs like that..." (P2)*

#### **Theme 7: Enjoy active socializing**

This theme means participants can be given access to live in harmony and contribute to the community, in this case at the Empowered House. This is in line with the El-Monshed and Amr, 2020 study that the quality of social support plays

an important role in the recovery of PSW which shows they have strong social and high emotional support and tend to experience better recovery. This theme answers the specific goal, namely to explore the meaning of the recovery process experience for PSW. This is in accordance with the concept of the CHIME framework which is included in the meaning of life where they can live and interpret their lives according to their social goals. Hence, they can actively socialize without any differences. The participants also expressed high expectations to socialize again and there was no resistance from everyone when they started interacting and had access to interact. Therefore, an effective social functioning depends on the ability to optimally move away from social rejection and move toward social rewards (Fulford et al., 2018).

The sub-theme of being able to socialize means that this empowered house is a place for the participants to interact and learn skills. The statements that support this sub-theme are:

*"...This empowered house is a place for people to gather for people who have problems, a place to share their experiences like that..." (P2)*

*"...I consider this house as my house...my family here because everyone accepts me as a family here..." (P3)*

*"...Here, the house plays a big role for me...instead of doing nothing at my own house, right..." (P4).*

*"...helping friends who, in this case, still isolate themselves at home, don't have access to socialization...So we feel much benefits of this empowered house, we must gather like that..." (P5)*

#### **Theme 8: Situations that affect self-ability**

This theme is a situation that comes from a condition that influences the participant. Study Nemoto et al. 2019 showed PSW who can defend themselves despite their low social competence have mild social anxiety symptoms, compared to those who are incompetent. This anxiety causes them to hesitate to socialize with others and inhibit social functions, hence affecting their ability (Nemoto et al., 2020). Contributions from various parties are needed for the healing process in mental health services in the community by aligning a comfortable environment (Beckers et al., 2020),[36]. The sub-themes include being affected by friends and being hampered by the covid-19 pandemic

The sub-theme of being affected by friends means as participants' moods and behaviors will influence each other. When participants are being less enthusiastic in doing activities, thus it will affect other people at the empowered house, as shown below:

*"...The problem is, I'm here, sometimes...I've also felt lazy, even though I've taken the medicine..." (P1)*

*"...the bad thing is that smoking is affected by friends...who previously didn't smoke, are now smoking..." (P4).*

*"...When I'm a bit so lazy, it means that my friends are also not enthusiastic...it affects me too..." (P5)*

*"...but if my friend is excited, I am also excited..." (P5)*

Being hampered by the covid-19 pandemic, this sub-theme is closely related to current conditions, where the covid-19 pandemic limits participants from carrying out activities and engage with friends at the empowered house. Participants' statements related to this sub-theme are:

"...The obstacles, yes, the simple ones are because of this pandemic...what exists is because of this pandemic, it's a bit difficult to come here..." (P3)

"...In this covid season, friends can't gather that much...that was so sad" (P5)

### **Back to being a part of the community**

This is a major theme that includes eight existing ones. When this is associated with the concept of the recovery process, the CHIME framework becomes the goal. Hence, it becomes connectedness, hope, and optimism. The self-identity, meaning of life, and empowerment that occur in the recovery process all aim to return to being part of the community. Chaudhari *et al.* 2018 stated that the success of therapy in PSW does not only lie in the psychopharmaceutical process and other types of therapy, but the role of the family and community is also decisive (El-Monshed & Amr, 2020). This opinion becomes a reference that the theme of returning to be part of the society is the last process for PSW whether they are ready to carry out activities as usual and lead a normal life again.

### **LIMITATION OF THE STUDY**

The following are some of the research's limitations that researchers have encountered: the use of audio-visual, which was planned, but in the end, all participants were only recorded with audio. Researchers are unable to identify participants because the conditions of people with schizophrenia at home are so varied, and there are still those who are unable to communicate effectively. The researcher did not delve deeply into the participants' past experiences, heeding the advice of the officers at Empowered House during the interview not to do so.

### **CONCLUSIONS AND SUGGESTIONS**

The concept of recovery process based on the CHIME framework is very well applied in rehabilitation centers in the community. This study showed positive outcomes for the recovery process of people with schizophrenia who are getting better than when they first entered the empowered house. Being part of the community means that people with schizophrenia recognize their identities, have a meaningful life and be empowered in the community.

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### **ETHICAL CONSIDERATIONS**

Ethical approval was obtained from the Research Ethics Commission, Faculty of Medicine, Udayana University/Sanglah Central General Hospital Denpasar with number 1192/UN14.2.2.VII.14/LT/2021.

### **Conflict of Interest Statement**

I declare that the publication of this paper does not involve any conflicts of interest.

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