Experiences of the Recovery Process and Support for Patients with Schizophrenia in Japanese Psychiatric Hospitals

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ABSTRACT

Background: Psychiatric treatment in Japan is shifting from hospital to community-based care. However, many patients require re-hospitalization in the short term, indicating that recovery support is insufficient and does not correspond to the needs of patients.

Aim: In this study, nine community-dwelling patients with schizophrenia were interviewed regarding their experiences from hospital admission to discharge and their return to community life.

Method: Data from interviews were transcribed and analyzed using qualitative descriptive methods.

Results: The participants described encountering the unknown and tried self-coping, but were still being hospitalized in crisis. In the hospital, they experienced distress in the closed environment; however, they also received support that ensured security and motivation, and were able to confront their distress, transform themselves, and leave the hospital. They described their experiences of having symptoms and regarding community life concerns, but were still able to accept things as they were and obtain support, which gave them hope. Finally, they described realizing recovery from illness and seeking a way of life with goals.

Conclusions: This study demonstrated the recovery process (patients learning to help themselves and increase their resilience), as well as the protection of patients' human rights (listening to their subjective and informed experiences).

Key-words: Schizophrenia, experience, recovery, support, psychiatric hospital

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I. Introduction

Schizophrenia is a complex, chronic mental health disorder characterized by an array of symptoms, including delusions, hallucinations, disorganized speech or behavior, and impaired cognitive ability. The goals in treating schizophrenia include targeting symptoms, preventing relapse, and increasing adaptive functioning so that the patient can be integrated back into the community. While pharmacotherapy is the mainstay of schizophrenia management, nonpharmacological treatments, such as psychosocial therapy, are also important.

In recent years, recovery has become a guiding concept for practice in global mental health services. Recovery, in this context, refers to personal recovery. It is the deeply personal and unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying and hopeful life where one feels they are making a contribution, even with the limitations caused by an illness. This involves the development of new meaning and purpose in life as one grows beyond the catastrophic effects of mental illness.

Personal recovery can occur with or without remission of symptoms. In contrast, clinical recovery is identified by the remediati

When discussing personal recovery, it is also important to consider how this process fits within the mental healthcare system of a particular country. In this regard, several studies have discussed cultural differences in the conceptualization of personal recovery; however, there is a paucity of Japan-specific research, indicating the need to develop a recovery model tailored to the country.

Following the lead of other countries, in 2004, Japan released “The Vision for Reform of Mental Health and Welfare” to promote the transition from hospital to community-based care. Further, the importance of mental health services based on the concept of recovery was emphasized; however, as of 2017, the average length of stay in psychiatric hospitals in Japan was 265 days, much longer than in other parts of the world.

Globally, psychiatric inpatients have reported poor experiences of mental healthcare that are not conducive to recovery. Concerns include coercion by staff, fear of assault from other patients, lack of therapeutic opportunities, and limited support. This is likely caused in part by the focus within psychiatric mental health services on the biomedical model, as well as the organizational focus on maintaining safety and clinical treatment, over person-centered, recovery-oriented practice. For example, schizophrenia treatment in Japanese psychiatric hospitals does not involve recovery support that is responsive to patients’ needs. Within this context, it is important to explore the lived experiences of patients with schizophrenia who were admitted to and discharged from psychiatric hospitals in Japan.

Therefore, in this study, community-dwelling people with schizophrenia in Japan were interviewed about their experiences from admission to a psychiatric hospital to discharge
and their return to community life. The findings from these interviews will have implications for recovery support for patients with schizophrenia in Japanese psychiatric hospitals.

II. Objectives

In this study, nine community-dwelling patients with schizophrenia were interviewed regarding their experiences from hospital admission to discharge and their return to community life.

III. Methods

1. Study Design

The current study is qualitative in design. The qualitative descriptive approach used in this study lies within the naturalistic approach in which the researcher understands phenomena through the meanings participants ascribe to them. Qualitative description aims to produce a clear account and comprehensive summary of a targeted phenomenon using participants’ language, staying close to the data.

2. Study Period

From April to September 2013

3. Participants

This study was carried out in Aichi prefecture, Japan, where treatment for community-dwelling people with schizophrenia is primarily outpatient or psychiatric daycare. Psychiatric daycare is typically offered to individuals who have just been discharged from inpatient care or as a more intense treatment for people who have failed to respond to outpatient care. Participants for the current study were recruited from psychiatric daycare and were required to meet the following inclusion criteria:

(1) be diagnosed with schizophrenia
(2) have previously been hospitalized for schizophrenia
(3) have attended psychiatric daycare in the past four years
(4) have the ability to talk about their own recovery
(5) consent to participate in the study
4. Data collection

Semi-structured interviews covering the following three topics were conducted:

(1) background prior to psychiatric hospitalization
(2) experiences during psychiatric hospital stay until discharge
(3) community life using psychiatric daycare

Nine participants were interviewed individually in a private room at the day care after their programs or during free time while on programs. Each interview took about 60 minutes to complete. Interviews were recorded with each participant’s consent.

5. Data analysis

Transcribed data from the interviews were analyzed using qualitative description. All transcripts were read repeatedly and relevant text was extracted and labeled using short sentences as first codes. Then, the first codes were categorized based on similarity and named based on their common meaning as second codes. This cycle of categorization was repeated until the final codes were generated. The final codes were labeled “categories” and the codes that made up the categories were labelled “subcategories”. The relationships among categories were examined with consideration for how they influenced one another.

The nine participants checked the results of the analysis to ensure credibility. Three nurse researchers specialized in psychiatric nursing and with experience in qualitative research verified the validity of the results through comparison with their prior practice and knowledge.

6. Ethical considerations

The study was approved by the ethics committee at Aichi Medical University College of Nursing (No. 51). Each participant received an explanation of the study and was informed that participation was voluntary and that their anonymity would be protected. Written informed consent was obtained from all participants.

IV. Results

1. Basic attributes (Table 1)

Nine participants with schizophrenia were individually interviewed (see Table 1). Their average age was 41.4 years, and they had been attending psychiatric day care for an average of 1 year and 11 months. Eight of them lived with their families and one lived alone. The average interview duration was 67 minutes.
<Table 1> Basic attributes

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2. Recovery and support as described by study participants

Seven categories were extracted from the analysis of the narratives of the nine participants. Each category is described below, with subcategories indicated by the use of [brackets] and supplements in (brackets)

1) Category 1: Encountering the unknown, self-coping, but still being hospitalized in crisis

The participants had the experience of being [surprised by suddenly encountering voices and radio waves] at work and home.

When I was at home, I suddenly heard a voice saying, “I'm going to strangle you,” and I got scared.

It was strange. I don't know what it was. I thought I was hearing radio waves coming into my head, communicating over the airwaves.

They experienced physical fatigue and [pain caused by physical reactions] while working, which disrupted their daily lives.

I had this thing about my muscles not feeling right, but I was working through the pain.

I worked two shifts and my body clock went crazy. It became too irregular to do anything.

To alleviate this feeling, the participants described [destroying oneself in order to cope].
I was so scared that all of a sudden, I ran out of the house like crazy. I killed my feelings because I couldn't trust people anymore. I've self-harmed and tried to kill myself.

Immediately prior to their hospitalization, the participants described experiencing a state of confusion and [crisis in which they were unable to control themselves].

I got into an argument with my mother and kicked the door down. I got into a fight with my sister, and I couldn't stop myself from getting upset, so I hit her. I lost my temper and stuck a kitchen knife through the bran. I was yelling at him and got upset. I rode my bike on the sidewalk, and the cops grabbed me.

They were hospitalized voluntarily or by family members after they or their family [gave up on continuing community life].

My parents told the doctor that they couldn't take care of me, so I had to be admitted. I thought it wasn't good, and the doctor told me “It was bad.” I was immediately admitted to the hospital. My mother's helper called it in and I was forcefully hospitalized.

2) Category 2: Distress in a closed hospital environment

All participants were admitted to closed wards, and some were admitted to isolation rooms. They [endured the suffering of not being able to get out] while in these closed wards and isolation rooms.

I couldn't stand the pain (in the isolation room); I was going round and round in circles all day. I asked nurse and the doctor to let me out but they wouldn't, so I broke down crying.

The participants also felt distrustful and fearful of the other patients and medical staff they encountered in the wards and were [endured the suffering of not being able to get out].

There were so many broken people (other patients), it was shocking to watch. I saw other patients screaming and I wondered when they would take me too; I was scared.

When I asked him (the doctor) why I couldn't go outside, he said it was because I might not get along with everyone. That's when I lost faith in him.

The nurses said to me, “Please come in, just for a look in the ward.” The moment I did, they closed the door. When I asked to see my family, I was told that they had already left, which shocked me.
3) Category 3: Support that ensured security and motivation

The participants described [healthcare providers who understood the distress of hospitalization] in a closed hospital environment.

The nurse asked the doctor to help me get out (of the protection room). I’m glad I had someone who understood me.

The participants also stated that there were [other patients aiming to be discharged together] in the closed wards.

A patient in the hospital said, “Eat your food and you’ll be checked out. If you don’t eat, they won’t let you leave the hospital.”

We made friends and tried to escape together.

One participant was moved by the fact that family members came to visit them and [treated them like a member of the family].

I didn’t think she would come. When she came, my heart, which had been quiet and still, lit up like a flower. She made me forget the distress I was going through.

It saved (my) heart. I realized that what I wanted most was to see my family.

4) Category 4: Confront distress, change yourself, and leave the hospital

The participants went from struggling in a closed hospital environment with the people they met there to [confronting their distress and feeling signs of recovery] on their own, with the support of medical staff, other patients, and family members.

I was mentally down and went to get an abortive to calm me. The nurses praised me and made me feel like I could do it myself.

Occupational therapy was very hard for me. But by working hard at it, I heard scary voices less and less.

They were beginning to experience signs of recovery, in contrast to the post-discharge life they had envisioned. They described being [discharged from the hospital in accordance with the conditions of discharge and making concessions for those around them], that is, their families and medical staff.

My mother told me, “You won’t be able to stay at home forever after you leave the hospital.” The nurse also told me, “If you can’t go to daycare, you won’t get a good job.” I wanted to get out of the hospital, so I decided to go (to psychiatric daycare).

5) Category 5: Symptoms and community life concerns

The participants encountered [persistent psychiatric and physical symptoms] while living in the community and using psychiatric daycare.

When I have auditory hallucinations and I panic in the morning, I can’t get on the subway.

Sometimes, I wanted to die because my muscles caused so much pain.

They also had [worries about the disease itself and community life].

It was hard for me to accept the reality of my schizophrenia when I saw my friends
at the reunion getting married and raising kids.
I had no money because I couldn’t get through the living expenses process. It was
the scariest thing.
I didn’t know anyone (in the area), so I was living a lonely life on my own.

6) Category 6: Accepting things as they are and support for hope
In contrast to Category 5, participants reported that their [encouraging family]
supported them.

My aunt encouraged me, saying, “It’s hard that you’re sick, but you have to stay
cheerful.” She encouraged me to start from where I could.

Further, one participant reported that they had met other [daycare members who
shared their concerns].
When I told my friend at daycare about my concerns, she was with me and made
me feel safe.
Furthermore, as they had access to [professional staff to attend to their concerns], they
were able to achieve mental stability and resolve their problems.
I’m glad my doctor is almost like a friend who understands that late night shows
are funny and gives me input on my English studies.
I found a psychotherapist who was there for me when I needed to be listened to,
and who was very approachable.
I went to a psychiatric social worker for advice and was able to get some money to
live on. I rely on my worker to help me with anything I don’t understand.

7) Category 7: Realizing recovery from illness and seeking a new way of life with goals
Several participants described having some worries about their mental illness
immediately after discharge, but that by using psychiatric daycare, they felt that they had
[recovered from mental illness].
I have a better rhythm in life now that I’m in psychiatric daycare. I have a
foundation for my life.
Strangely enough, I don’t hear scary voices anymore.
No more schizophrenia derailing my thoughts.
I can talk about my feelings now.
I got to see fireworks, which I haven’t seen in 10 years.
It’s easier to get out.

In addition, several participants spoke of [having a goal in life].
My goal is to learn to talk about myself successfully in daycare so that I can live in
society without a counselor.
Right now, my goal is to work at a continuous employment support facility.
It’s about staying healthy.
The participants also described still [searching for the way to live from now on], even though they were making an effort to get closer to their goals.

I don’t know what to do, and I don’t know what the future holds.
I knew that if I didn’t work, I wouldn’t have enough money to buy anything. That’s why I went to the lunch box work experience. But I thought it wasn’t for me.
I need to find a job, but I’m not sure I can do it.
I want to have friendships, but it’s hard for me. I’m not good at making friends on my own.

3. Relationships among categories

There were also relationships among the aforementioned categories. Specifically, (Category 1) encountering the unknown and self-coping, but still being hospitalized in crisis, describes when they encountered the disease, and their experience of being [surprised by suddenly encountering voices and radio waves] and experiencing [pain caused by physical reactions]. They were [destroying oneself in order to cope] but were in a state of [crisis in which they were unable to control themselves] and were forced to [give up on continuing community life and resigned themselves to hospitalization].

When they entered a closed psychiatric hospital or isolation room, they experienced (Category 2) distress in a closed hospital environment, such as [enduring the suffering of not being able to get out] and being [hurt by the words and actions of other patients and medical staff]. However, with (Category 3) support that ensured security and motivation, they were able to overcome this distress. With [healthcare providers who understood the distress of hospitalization], [other patients aiming to be discharged together], and family members who [treated them like a member of the family] they were able to alleviate their distress.

They described gradually [confronting their distress and feeling signs of recovery]. However, different from the life they had envisioned, they were [discharged from the hospital in accordance with the conditions of discharge and making concessions for those around them]. This experience was named (Category 4), confront distress, change yourself, and leave the hospital.

They returned to community life, but they still had (Category 5) symptoms and community life concerns such as [persistent psychiatric and physical symptoms] and [worries about the disease itself and community life]. However, they also described (Category 6) accepting things as they are and support for hope with the help of [encouraging family], [daycare members who shared their concerns], and [professional staff to attend to their concerns]. They [recovered from their mental illness] and described [having a goal in life], while [searching for the way to live from now on], together described as (Category 7), realizing recovery from illness and seeking a new way of life with goals.

Thus, Categories 1–7 can be used to describe the recovery process as a time series (see Figure 1).
<Figure 1> Recovery Process and Support
V. Discussion

1. The process from psychiatric admission to living in the community involves learning to help yourself and building resilience

Prior to admission, the participants experienced the unknown (i.e., positive and negative symptoms of schizophrenia). They attempted to self-manage their symptoms but were unsuccessful, leading to a crisis state and eventually hospitalization. During the period from their first encounter with the illness to hospitalization, they became helpless.

Upon admission, they participated in a variety of programs, including the use of antipsychotic medications to alleviate psychiatric symptoms and allow them to be discharged from the hospital. The experience of being in a closed environment and being forced to participate in treatment and rehabilitation was distressing. However, this was an opportunity for them to learn coping skills, such as asking someone for help and actively engaging in occupational therapy.

At the time of discharge, participants described how their wishes were rejected and the conditions for their discharge were proposed by family members and healthcare providers. They coped with this obstacle by giving in to the opinions of those around them in order to achieve their own goal of discharge. In this respect, the self-coping skills they acquired during their hospitalization were applied to their community life at psychiatric daycare.

Thus, experiencing schizophrenia was clearly a learning process in which patients actively attempted to overcome the illness, rather than one in which the illness dominated them. They were very positive about their discharge and this process of learning and practicing appropriate self-coping strategies in the face of hardship can be seen as “resilience” building, enabling them to overcome traumatic and stressful events. This enhanced resilience facilitated recovery.

2. The meaning of support: A human rights advocacy stance that listens to individuals’ subjective experiences

The participants described being distressed by their admission to psychiatric hospitals. However, they were supported by medical care providers who understood them, other patients who had the same goal of discharge, and their families. Even if they had problems in their community life after discharge, they were supported by psychiatric daycare members who spent time with them and family members who encouraged them.

What these supporters had in common was their ability to listen to their subjective experiences and defend their human rights, allowing them to engage as people, not simply ill people. By examining the meaning of each person’s unique illness, supporters are able to break the vicious cycle that amplifies suffering and instead provide more effective care. Therefore, healthcare providers’ respect for patients’ freedom, their recognition of patients as human beings and experience-informed individuals will lead to increased resilience. This is relevant not only for healthcare providers but also for family and peer supporters.
3. Issue in supporting patients with schizophrenia in Japan: recovery orientation

The participants had experiences in psychiatric hospitals that were not in accordance with their wishes, including forced inpatient treatment, problems with medical staff, rehabilitation that they did not want, and unfavorable conditions at discharge. This is partly due to common psychiatry practices in Japan, including forced treatment, involuntary hospitalization, and restraint, which infringe on patient autonomy and respect.

They experienced the loss of their individuality by being hospitalized, where they were treated as part of a group and had to follow the unspoken rules of inpatient life. Furthermore, they were discharged from the hospital to fulfill their obligation to recover and to cooperate with the healthcare professionals, concentrating on medical treatment and playing the expected patient role in order to be able to carry out their original social role again.

The reason for this phenomenon is that there is a significant difference between the perspectives of patients and medical staff. In treating patients with schizophrenia, attention to the client's subjective views is fundamental to recovery-oriented care, and cultural sensitivity and the ability to imagine the experience from the client's perspective are also important. In this respect, patient experience is a vital source of evidence that can drive the provision of high-quality healthcare services.

Japan has a longer average length of hospital stay than many other countries. As a result, there are more medical staff working in psychiatric hospitals than daycare staff. To promote the recovery of people with schizophrenia in Japan, it is necessary for medical staff working in psychiatric hospitals to recognize that patients are individuals who will recover, and to provide recovery-oriented education that focuses on the subjective opinions of patients and supports them according to their needs.

VI. Conclusion

We identified seven categories and their relationships with the process from hospitalization to community life as described by Japanese patients with schizophrenia. The results demonstrated the recovery process (patients learning to help themselves and increase their resilience), as well as the protection of patients’ human rights (listening to their subjective and informed experiences). Despite this, the treatment process in Japanese psychiatric hospitals still cannot be said to be recovery-oriented. In the future, it is necessary to foster recovery-oriented practices in medical staff working in psychiatric hospitals in Japan.
Acknowledgments

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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## Original Articles

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<td>Current Status and Challenges of Interprofessional Work to Promote Independence in Excretion among Older People Requiring Care and Living in Provincial Cities; Focused on Roles of the Nursing College and Home Life Support services</td>
<td>Yoshiko ENOMOTO, et al.</td>
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<td>The Relationship Between Midwifery Practical Skills Evaluation and Midwifery Experience Among Young Midwives Working at Perinatal Medical Centers in Japan</td>
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<td>Factors Related to Preparatory Behaviors for the Death of Older Women who Lost Their Husbands before Old Age</td>
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