

Framework of subjective cognition in community-dwelling individuals with schizophrenia who experienced long-term hospitalization

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Abstract

This study was performed to elucidate the framework of subjective cognition about themselves and their life to date in individuals with schizophrenia who had experienced long-term hospitalization in a psychiatric hospital and were currently living in the community to support the life of these individuals in the community. Semi-structured interviews (about 30 minutes × 3 times per person) were conducted with eight individuals with schizophrenia living in the community for ≥ 1 year after having been hospitalized for ≥ 3 years in total (including one hospitalization period lasting ≥ 1 year). The KJ method, an affinity diagram developed by Kawakita that serves as a tool for organizing ideas and data, was used to divide interview data into 10 groups, or islands: “*wanting to escape from the negative situation*,” “*being admitted to hospital = assurance of security*,” and “*turning to religion for salvation*” indicating hospitalization as an uncontrollable situation with a strong sense of powerlessness, and “*not being afraid of the past*” and “*fighting to avoid re-hospitalization*,” showing that after hospital discharge, individuals with schizophrenia looked for a place where they could keep some distance from their past and exert some control over the present. While living in the community, they were secretly “*yearning for marriage*,” while “*keeping an easygoing attitude about their position in society*,” “*trying to overcome the barriers between themselves and healthy individuals*,” and “*being encouraged by the realization of being ordinary*,” suggesting that they longed for their own place in the community. Finally, “*learning from agonizing events to change oneself*” suggested that individuals with schizophrenia intend to change themselves through their various experiences during and after hospitalization. Taken together, these findings suggest that to provide adequate care to individuals with schizophrenia living in the community after long-term hospitalization, it is necessary to understand their views about community life, in addition to understanding their past medical history, especially prolonged hospitalization, which constitutes a large part of their outlook on life and the world. It is also important to conform to their pace because individuals with schizophrenia tend to have challenges with voluntary impulse control.

KEY WORDS

Schizophrenia, long-term hospitalization, community life,
a subjective point of view, KJ method.

Introduction

The government of Japan strives to support individuals with mental disorders by improving both the medical and welfare systems. First, the government amended the Basic Act for Persons with Disabilities in 1993 to clearly

designate individuals with mental disease as persons with disability. Following this amendment, the Act on Mental Health and Welfare for the Mentally Disabled was passed in 1995 to provide welfare services for individuals with mental disorders, by amending the Mental Health

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Act regarding psychiatric care, to include articles related to welfare. Consequently, healthcare professionals involved in the care of individuals with mental disorders were required to have skills for managing psychiatric symptoms and functional impairment due to mental disorder as well as living difficulties and social disadvantages. Today, because the goal of mental health, welfare, and medicine is to achieve a high quality of life, it is extremely important to support community-dwelling individuals with mental disorders.

A patient survey conducted by the Ministry of Health, Labour and Welfare (2014) revealed that mental and behavioral disorders are most prevalent among individuals with schizophrenia¹⁾, suggesting that many community-dwelling individuals with mental illness have schizophrenia. Many mental disorders, including schizophrenia, are more likely to manifest during adolescence^{2, 3)} and run a chronic course for a prolonged period. Therefore, it is essential to support individuals with mental disorders throughout their lives, instead of simply treating an individual disease in isolation. In providing satisfactory medical care, it is important to clarify subjective cognition in individuals with mental disorders to understand their perception, assessment, and interpretation of the world around them.

The key to understanding subjective cognition in individuals with schizophrenia is in their own words. Language allows for expression of self-image by self-awareness and is modified by self-control⁴⁾, thus establishing a reciprocal relationship between oneself and society. Therefore, it is possible to get to know a person and how they perceive the environment from their stories. Previous studies used subjective cognition, as revealed in stories from individuals with schizophrenia, as information to assess their psychiatric symptoms⁵⁾ or analyze the difference in judgment between individuals with schizophrenia and healthy individuals⁶⁾. Eventually, subjective cognition has come to be known as a feature that expresses the quality of life or living conditions of these individuals, and Iwawaki (1997) has also identified the utility of subjective cognition in rehabilitation⁷⁾.

Hospitalization intensifies a sense of detachment from everyday life in individuals with mental disorders who have experienced long-term hospitalization or were hospitalized against their will⁸⁾. Therefore, it is conventionally thought that hospitalization is recognized

as a sensitive issue for individuals with mental disorders in retrospect⁹⁾. However, in a study using a phenomenological approach, Anderson (2014) reported that African-Americans with schizophrenia view their life with the disease as a gift¹⁰⁾. Japanese studies analyzing stories by individuals with schizophrenia have also reported the significance of schizophrenia^{11, 12)}, motivation in daily life¹³⁾ and subsequent positive conditions¹⁴⁾. However, no study has requested individuals with schizophrenia to talk about life in general, including past hospitalization, in the community. To provide adequate long-term care while supporting and offering guidance to individuals with schizophrenia, it is essential to understand past long-term hospitalization, which constitutes a part of their lives, current living conditions, and future prospects.

Therefore, in this study, we aimed to elucidate the framework of subjective cognition about themselves and their life to date, in community-dwelling individuals with schizophrenia who have experienced long-term hospitalization. The findings will provide insight for how to support the life of these individuals in the community.

Definition of terms

1. Long-term hospitalization: If the total duration of individual hospital stays, including one period lasting ≥ 1 year, was ≥ 3 years, the patient was said to have experienced long-term hospitalization. Also, due to a high rate of recurrence/relapse in patients with schizophrenia, community life is often interrupted by rehospitalization. Therefore, the total duration was set to include individuals who had experienced long-term hospitalization due to rehospitalization.

2. Subjective cognition: The perception, assessment, and interpretation of objects in the environment. "Cognition" differs depending on the context or layer. We defined the term "cognition" in a broad sense.

Methods

1. Subjects

Interviews were conducted with eight individuals (five men, three women; mean age, 50.0 ± 7.6 years) with schizophrenia who lived in the community for ≥ 1 year after having been hospitalized for ≥ 3 years in total (including one hospitalization period lasting ≥ 1 year). The characteristics of these individuals are summarized

in Table 1.

The mean age of onset was 22.0 ± 4.8 years, and mean hospitalization frequency was approximately 3.8 ± 2.6 times. The mean of longest hospital stay was approximately 10.9 ± 11.8 years, and mean total years was approximately 13.6 ± 10.9 years. The mean of years after hospital discharge was 10.0 ± 5.6 years. These three are approximations because some participants could not remember the exact data.

All participants were employed: three had regular full-time ($n = 2$) or part-time ($n = 1$) jobs and five were employed at vocational centers for persons with disabilities. All of them were single, one had divorce history. One participant lived with his/her family, three lived in their group home, and four lived alone.

Inclusion and exclusion criteria used in this study were age ≥ 20 years, capacity to describe their stay in hospital and treatment received, absence of mental retardation or dementia, and hospitalization ≥ 3 months in total during the last 1 year. Some participants were recruited through peer group counseling and were fully informed of the purpose and method of the study. Other participants were introduced to us by facility managers (two nursing departments in general hospitals and one vocational center) and had consented to participate in the study after having been fully informed of the purpose and method of the study.

2. Interview

A semi-structured interview lasting approximately 30 min was conducted with each participant 3 times. The reason for conducting short interviews multiple times was to make participants more comfortable so that researchers could obtain more information. Mean interview duration was 39 min 21 sec (shortest, 25 min;

longest, 1 h 30 min). Interviews were conducted in a room where privacy was assured, and the interview was recorded using a digital recorder and transcribed after obtaining consent.

The aim of the interview was to ascertain how participants spend their days presently and if they have any recollection of their prolonged hospital stay. We listened to them carefully without interruptions, unless absolutely necessary, letting them recall, contemplate, feel, and talk about community life in the present and hospitalization in the past. We had additional questions if past events or facts were unclear. When we could not understand their stories that expression was different from general, we asked for further explanation. And we talked the topic in other words for taking their check.

In the first interview, we asked to talk about the current life, and their present state of illness. On the following interview, after confirming the previous remark, we asked about their past hospitalization. In the last interview, we confirmed the previous contents and asked if they wanted narrating further. Everyone finished talking about the current topic of life in the 3rd interview. One participant had only 2 interviews due to personal reasons.

3. Structuring data

We aimed to extract themes from people with diverse backgrounds without distinguishing between length of hospital stay etc. Verbatim transcripts were carefully generated from interview data, and data structuring was performed using the KJ method (Kawakita, 1967)¹⁵⁾, an affinity diagram for extracting the essence of a theme (study items) from disordered language data. The method gathering information is inspired from chaotic data itself. It is not based on fixed quantitative data

Table 1. Summary of study participants

Participant	Age (decade)	Gender	Age of onset (years)	Hospitalization frequency (times)	Longest hospitalization (years)	Total years of hospitalization (years)	Years after discharge (years)	Working experience (yes / no)	Marital status	Resident type
A	50	Male	30	3	12	16	14	yes	divorced	alone
B	40	Male	21	1	21	21	8	yes	unmarried	group home
C	60	Male	20	3 *	35	37 *	5	yes	unmarried	alone
D	50	Female	28	3	5	8 *	15	yes	unmarried	alone
E	40	Female	15	4	2	6 *	16	yes	unmarried	family home
F	40	Female	21	1	9	9	15	yes	unmarried	group home
G	50	Male	20	7	1.5	5 *	2	yes	unmarried	group home
H	60	Male	21	8	1.5	7 *	5	yes	unmarried	alone
Mean \pm SD	50.0 ± 7.6		22.0 ± 4.8	3.8 ± 2.6	10.9 ± 11.8	13.6 ± 10.9	10.0 ± 5.6			

*: These data are approximations because some participants could not remember the exact data.

and it does not verify a hypothesis but rather inspires a hypothesis itself.

Interview contents related to the study theme were extracted from verbatim transcripts, properly unitized and compressed without changing the context, and then labeled to create an affinity diagram. Labels placed on the diagram were carefully selected using the multi-stage pickup procedure.

Selected labels were used as original labels to perform the narrow-sense KJ method. Using the overall features of the original labels as background information, labels were grouped into sets based on relative proximity of quality. Each set of labels was given an integrated concept called a nameplate. Labels that did not make a set were designated loners.

Integration by grouping was repeated until ≤ 10 labels remained, which were used to create an illustration. Integrated labels on an illustration were designated as islands, and each island after the final integration was given a symbol concept called symbol mark. Islands were arranged to maximize the persuasiveness of the data structure, and qualitatively close islands close to each other in terms of quality were surrounded by dashed lines to show that they were related.

To ensure the reliability and certainty of the results, the authors attended a workshop on the KJ method and took personalized lessons on labeling, name-plating, illustration, and predication to accurately structure data acquired from study participants according to the methodology. Furthermore, our study was reviewed by researchers who were familiar with qualitative research to ensure the validity of the study results.

4. Ethical considerations

This study was approved by the Ethics Committee of Kanazawa University School of Medicine (approval No.:614-1, July 8, 2015). Special attention was paid to avoid pressuring participants introduced by facility managers who consented to participate in the study. Before signing a consent form, participants were fully informed, verbally and in writing, of the purpose and purport of the study, the right to withdraw from the study, the protection of personal information, and the voluntary nature of participation. Interview was interrupted promptly to allow for a rest break when talking about past experiences that caused participants to feel sick mentally or physically.

Results

In total, eight individuals with schizophrenia were interviewed during the data collection period (November 2015 – May 2017), none of whom requested to withdraw.

Using the KJ method, verbatim transcripts were labeled, and carefully selected labels were integrated into 10 groups (islands). Verbatim transcripts were read carefully, and 169 contents seemingly related to the study theme were labeled and arranged to create an affinity diagram. Multistage upscaling was performed to narrow this down to 65 labels to be used as original labels in the narrow-sense KJ method. Eventually, the 65 labels were integrated into 10 groups (islands) by repeating the grouping.

Islands with similar qualities were placed close together to develop a structure with logical persuasion. Regarding some nearby islands, we surrounded by dashed lines, and expressed the relationship among the islands with the symbolic lines. Based on such conceptual visual map using labels, we made description so that they would be appropriate stories.

The time course of the storyline was set from the past to present, as below. Data were expressed as label (“”), first-stage nameplate, second-stage nameplate, third-stage nameplate, and symbol mark (italic letters). Figure 1 was a schematic illustration of the results of grouping and symbol marks. Table 2 showed the results of structuring after the second-stage.

Past hospitalization was expressed as “*wanting to escape from the negative situation*,” “*being admitted to hospital = assurance of security*,” and “*turning to religion for salvation*,” showing that individuals with schizophrenia felt strongly about having been unable to recognize or control the disease. They felt hospitalization was unwarranted, but at the same time, they felt safe and protected from the harshness of society and turned to religion for salvation because of strong feelings of helplessness and powerlessness. After hospital discharge, individuals with schizophrenia tried not to be bothered by past hospitalization and wanted to maintain their mental health to avoid rehospitalization, and thus consciously distanced themselves from the past, as shown by “*not being afraid of the past*” and “*fighting to avoid re-hospitalization*.” Also, as revealed by “*keeping an easygoing attitude about their position in society*,” “*trying to overcome the barriers between themselves and healthy*

individuals,” and “being encouraged by their realization of being ordinary,” individuals with schizophrenia actively searched for a way to find their own place in the society, actively looked for a place to stay by evaluating themselves comfortably and positively, and secretly had “yearning for marriage,” all of which showed that they hope to secure their own place. “Learning from agonizing events to change oneself” indicates that individuals with schizophrenia tried to find the significance of their experience regardless of the severity of the experience or whether they were hospitalized or had been discharged. They were always positive about their lives and their relationships with the surroundings, willing to undergo self-transformation. By doing so, they lifted the center axis of their view of life and the world.

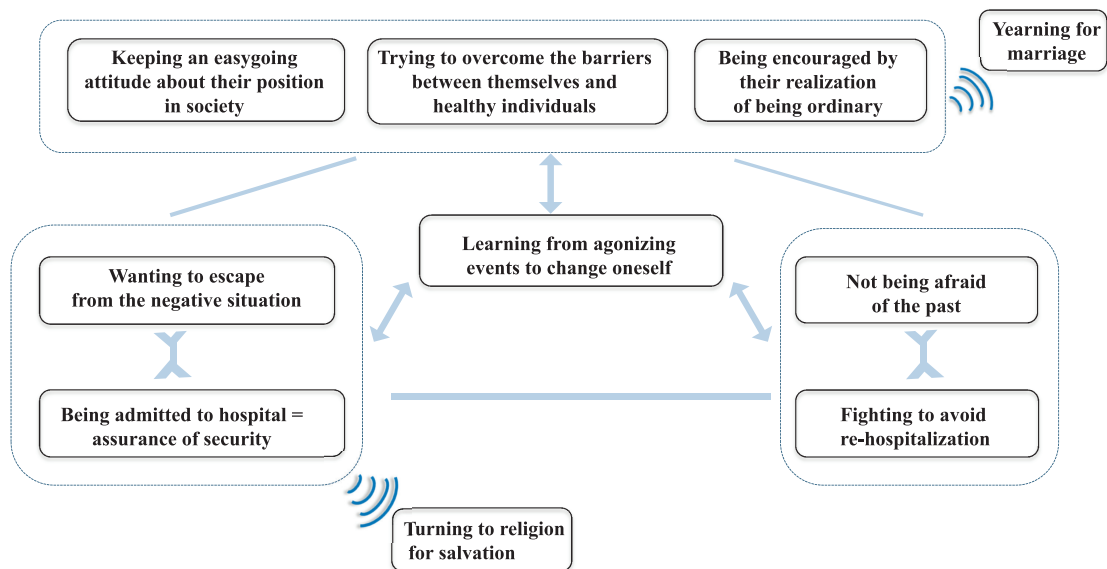
By paying attention to the cohesiveness of islands surrounded by dashed lines, each island is described carefully below.

1. Inability to recognize or control disease: “Wanting to escape from the negative situation,” “being admitted to hospital = assurance of security,” and “turning to religion for salvation”

Unlike in the past, individuals with schizophrenia were placed in situations where they could no longer control themselves because of hospitalization, which

was inevitable due to disease recurrence and relapse. Despite the concern of people around, hospitalization became an unwarranted experience because they were not convinced that hospitalization was necessary. Yet, they talked about things that made them feel secure by recalling the specifics of treatment environments such as hospital buildings, staff, and other patients undergoing therapy at the same time as they were. The content of their stories was thus ambivalent, showing that hospitalization was unwarranted but also made individuals with schizophrenia feel secure. Some of them turned to religion, which is beyond human understanding, for answers regarding unwarranted hospitalization due to disease.

Some subjective symptoms, such as hallucinations, are unrealistic and disconcerting. And thought disorders, such as delusions, make individuals with schizophrenia paranoid, disbelieving, and suspicious of the behavior of people around them. Because they usually do not have insight into their illness, individuals with schizophrenia felt they had to endure unwarranted hospitalization (to them) due to the lack of knowledge and understanding of the disease and treatment, even though people around them deemed that hospitalization was inevitable. Sometimes even if the symptoms are stable, feeling



- 1) Created date: 2018/03/09
- 2) Place of creation: Affiliated institutions
- 3) Source: Interviews with 8 individuals between November 2015 and May 2017.
- 4) Author: Kawamura

Island Nearby islands ※symbol mark : in bold,
 — : relationships, ↔ : interaction, >—< : inverse relationship,))) : influence

Figure 1. Challenge to regain significance and change oneself (symbol mark)

impatient and excessive strain on themselves made their condition worsened and hospitalized. Furthermore, patients were hospitalized longer to endure the severe adverse effects of drugs used at the time of disease onset, which prevented them from going back to work. In other words, patients who do not have sufficient knowledge about the disorder or treatment often fail to endure disease exacerbation or drug side effects, forcing them to be subjected to unwarranted hospitalization for a longer period.

In contrast, avoiding the stress of community life and being hospitalized gave individuals with schizophrenia peace of mind. When insomnia and psychiatric symptoms were improved and stabilized, they could then make friends with whom they could talk about the condition, sharing the severity of symptoms and sympathizing with each other. When they recognized themselves as sick persons who were somewhat ostracized by other people, they felt at ease specific to hospitalization and were comfortable because they felt absolved of all blame for their condition.

During hospitalization, individuals with schizophrenia turned to religion, hoping to change painful situations such as the disease itself and drug side effects. Although they continued to feel that a hospital stay remained unwarranted, they began to see their lives differently owing to religious teachings.

2. Search for a place to stand and have control: ***“Fighting to avoid re-hospitalization”*** and ***“not being afraid of the past”***

While regaining a sense of control during social rehabilitation after hospital discharge, individuals with schizophrenia faced realistic challenges associated with community life. After hospital discharge owing to recovery, life begins anew in a new environment, with an associated difficulty thinking and making decisions independently. In addition, when being treated at a hospital, it sometimes occurs to individuals with schizophrenia that they have a mental disorder. Therefore, they feel protected during hospitalization but anxious when living in the community. Yet, they wanted to not be caught up with the vulnerability of having been admitted to hospital for mental disorder in the past.

After hospital discharge, individuals with schizophrenia felt anxiety and had no confidence in developing new relationships or being in one, now that they

were out of hospital where they had a place of their own. Indeed, while struggling with the harshness of human relationships encountered in community life, many efforts have been made to prevent their health condition from deteriorating to the point where hospital readmission is required. This is because even though they made full efforts just to live well without going back, individuals with schizophrenia spend their days after hospital discharge mainly seeking and constructing a path to social rehabilitation. Outside the hospital, where they had a place to stay, individuals with schizophrenia strove to avoid re-admission despite severe anxiety and conflicts surrounding health conditions, new relationships, and financial prospects.

Outpatient treatment and home-visit nursing are essential for maintaining good health conditions, but they also remind individuals with schizophrenia about past hospitalization. Therefore, despite its connections with present life, past hospitalization is hidden where it seldom causes mental hang-ups. Even though some factors of current life bring up memories of their hospitalization, they tried to maintain the stance that it is not good to be caught up with the past. Furthermore, some individuals with schizophrenia placed an importance on the present life and said that for better or worse, the past hospitalization has nothing to do with the present life, just like simple tasks performed in occupational therapy are not applicable to their current job.

3. Subjectively talking a natural position in society: ***“Being encouraged by their realization of being ordinary,”*** ***“trying to overcome the barriers between themselves and healthy individuals,”*** ***“keeping an easygoing attitude about their position in society,”*** and ***“yearning for marriage”***

Conflicts occur in daily life. However, by making decisions by themselves, they get a sense of being able to keep things under control. While thinking that they are normal, not sick, and can make a life in the community, individuals with schizophrenia were also aware of the differences between themselves and healthy individuals and lived every day by taking note of things they can now do. They talked about a sense of longing for marriage in the future. During an interview, they assessed and carefully described their current lives and themselves.

Table 2. Challenge to regain significance and change oneself (from 2nd-stage to final integration)

2nd-stage nameplate and 2nd-stage loner	3rd-stage nameplate and 3rd-stage loner	symbol mark
Had to endure unwarranted hospitalization due to the lack of knowledge and understanding of the disease and treatment, even though people around them deemed that hospitalization was inevitable.	Those who do not have sufficient knowledge about the disorder or treatment often fail to prevent disease exacerbation or drug side effects, forcing them to be subjected unwarranted hospitalization for a longer period.	Wanting to escape from the negative situation
Even if the symptoms are stable, feeling impatient and excessive strain on themselves made their condition worsened and hospitalized.		
Hospitalized longer to endure the severe adverse effects of drugs used at the time of disease onset, which prevented them from going back to work.		
The merits of hospitalization were improvement and stabilization of insomnia and psychiatric symptoms, which enabled them to make friends with whom they could talk about their condition.	Felt safe and protected from negative reality during hospitalization because of improved symptoms, participating in fun events, and having someone to talk to.	Being admitted to hospital = assurance of security
Felt at ease specific to hospitalization and were comfortable because they felt absolved of all blame for their condition.		
Turned to religion, hoping to change painful situations such as the disease itself and drug side effects.		Turning to religion for salvation
Outside the hospital, where they had a place to stay, individuals with schizophrenia strove to avoid re-admission despite severe anxiety and conflicts surrounding health conditions, new relationships, and financial prospects.		Fighting to avoid re-hospitalization
Trying to maintain the stance that it is not good to be caught up with the past hospitalization, even though some factors of current life bring up memories of such as experiences during hospitalization and the reason for hospitalization.	Despite its connections with the present life, past hospitalization is hidden where it seldom causes mental hang-ups.	Not being afraid of the past
For better or worse, the past hospitalization has nothing to do with the present life, just like simple tasks performed in occupational therapy are not applicable to their current job.		
They encourage themselves, thinking that their disorder has improved compared with other people.	Having a job after hospital discharge may be perceived as a normal condition, and this is encouraging.	Being encouraged by their realization of being ordinary
All coworkers are sick and have a mental disorder, but they have maintained a good working condition after hospital discharge and therefore are not different from ordinary people.		
Cooperate with healthy individuals by deepening their understanding of what individuals with schizophrenia can and cannot do.		
Need to overcome many conflicts when coming out about disorder or seeking mutual understanding in a society where they interact with not only individuals with disability but also healthy individuals.	Always have obstacles to overcome, such as mutual understanding with healthy individuals and conflicts over coming out about disorder, regardless of whether at the time of disease onset, hospital admission, or discharge.	Trying to overcome the barriers between themselves and healthy individuals
Unable to deal with expectations from people around them or to turn to anyone for advice, which attributed to disease onset and hospitalization.		
Keeping the current job as a life discipline, without spending too much time and energy in thinking about the significance of work or increasing workload, and continue to live in the community with the help of others.		Keeping an easygoing attitude about their position in society
Have a strong desire for marriage.		Yearning for marriage
Willingness to build new relationships and make new friends expands life after hospital discharge and helps to transform themselves.	Thought they could change themselves during hospitalization and after discharge, by trying to expand their life potential, giving positive meaning to bitter experiences, actively creating ideas, and staying motivated about relationships.	Learning from agonizing events to change oneself
Current social life is supported by the fact that they have been tested by bitter relationships and experiences, such as the disorder and hospitalization, which inspires them to view themselves positively.		
When I re-examined my hospital days and time spent with other patients and hospital staff, I realized that occupational therapy provided ideas that were useful for work life after hospital discharge and that expanded the range of my action from being in a closed hospital ward to walking outside the hospital, thus leading to the future.		

By comparing themselves with those who are still hospitalized, they sometimes think their disorder has improved, which was one of the occasions leading to “being encouraged by their realization of being ordinary.” These individuals with schizophrenia were confident about themselves because they were no longer admitted to hospital and were healthy enough to work, and they also looked at other individuals with disorders as average members of a society, saying that “all their coworkers are sick and have a mental disorder, but they have maintained a good working conditions after hospital discharge and therefore are not different from ordinary people.” Having a job after hospital discharge may be perceived as a normal condition, and this is encouraging them.

On the other hand, these individuals with schizophrenia talked about the differences between themselves and individuals with no mental disorders, “trying to overcome the barriers between themselves and healthy individuals” and hoping to cooperate with healthy individuals by deepening their understanding of what individuals with schizophrenia can and cannot do. This is because individuals with schizophrenia need to overcome many conflicts when coming out about (their) disorder or seeking mutual understanding in a society where they interact with not only individuals with disability but also healthy individuals. What they learned from past hospitalization was that they were unable to deal with expectations from people around them or to turn to anyone for advice, which attributed to disease onset and hospitalization; this provided some insight into a healthy way of managing stress. This suggests that they will always have obstacles to overcome, such as mutual understanding with healthy individuals and conflicts over coming out about their disorder, regardless of whether at the time of disease onset, hospital admission, or discharge.

As reflected in “keeping an easygoing attitude about their position in society,” individuals with schizophrenia first accepted themselves as being different from other people before requiring others to understand them. Without spending too much time and energy in thinking about the significance of work or increasing workload, these individuals with schizophrenia continued to live in community life while keeping their current job as a life discipline, with the help of others. They lived in a group

home and kept a job with the help of others, considering work as a life discipline, instead of trying to be valuable to others. What is important in the first place is to keep the current job without putting too much strain on themselves. In other words, they defined work based on what it means to them by placing themselves at the core.

They would rather build a family with someone who understands them than live alone, thus “yearning for marriage.”

4. **“Learning from agonizing events to change oneself”**

“Learning from agonizing events to change oneself” was placed at the center as the view of the world that sums up the entire discourse. Individuals with schizophrenia thought (that) they could change themselves during hospitalization and after discharge, by trying to expand their life potential, giving positive meaning to bitter experiences, actively creating ideas, and staying motivated about relationships. They suffered from symptoms during hospitalization and were anxious about their limitations in community life after hospital discharge. The questioned how they would manage hidden triggers of symptom relapse or disease recurrence in community life. Their path to the future is by living their lives based on understanding their limits, knowing what they can do to control situations, and thinking about their potential. The practice self-control by focusing on changes in health conditions, but not simply on the possibility of hospitalization, showing that they are aware of the importance of controlling their conditions by themselves.

Individuals with schizophrenia gained hope for the future by making the best out of past experiences under the present circumstances. Willingness to build new relationships and make new friends expands life after hospital discharge and helps to transform themselves. Current social life is supported by the fact that they have been tested by bitter relationships and experiences, such as the disorder and hospitalization, which inspires them to view themselves positively.

Discussion

1. Special features of community-dwelling individuals with schizophrenia who have experienced long-term hospitalization

Despite its necessity, past hospitalization was viewed as an unwarranted experience by individuals with schizophrenia who had no insight into their disorder. Memories of past long-term hospitalization persisted, impacting their present lives. When individuals with schizophrenia who were currently being treated at an outpatient clinic looked back on their hospitalization experience, they felt a deep sense of isolation¹⁶. Emotional pain and negative experiences of these individuals with mental disorder during long-term hospitalization (from 2–22 years) turned into a source of stigma later⁹. Yet, the participants in this study had a positive view of hospitalization, even though they viewed it as unwarranted, because hospitalization interrupted an already unstable life, allowing them to regain their identity. The fact that they were now living healthy lives in the community may have been another reason for the positive view of long-term hospitalization from a neutral perspective.

Our participants have come to perceive themselves more positively after having been evaluated while living in the community. They experience repeated conflicts because community life inevitably makes them aware of how they are different from healthy individuals. Even when they accept their condition, people around them may not be as accepting because mental disorder evokes stronger negative emotions among Japanese than in other countries¹⁷. Individuals with schizophrenia are careful and selective about disclosure of their disorder and medical history, and they have peace of mind and increased confidence when accepted by others¹⁸. Community-dwelling individuals with schizophrenia are known to establish a new lifestyle, living conditions, and ways of coping with their disorder, before developing relationships with others¹⁹, suggesting that our participants' transformation depends on various experiences that teach them how much distance they, as individuals with disorder, should keep from the society.

In this study, individuals with schizophrenia were encouraged by their own striving in the society, but at the same time, they also tried to keep an easygoing attitude and accepted the fact that they were sometimes

ostracized or not received well by the society. Based on life experiences, community-dwelling individuals with schizophrenia changed their feelings about living with the disorder and modified their understanding of and measures for combating the disorder²⁰. They acquired peace of mind by accepting the current residence as their own place²¹. In the 1990s, a new concept about individuals with mental disorders emerged and began to spread²². This concept valued the process of finding the meaning and goal of a new life, while having hope despite prolonged psychiatric symptoms and functional impairment. Under this concept, the goal of rehabilitation was "recovery," which entails regaining the significance of their life, even when symptoms persist and "recuperation" is not in sight. Recovery is related to optimism, a belief that everything will be all right²³. When individuals with the disorder can make a life for themselves without forcing themselves to fit into society, it would eventually lead to vital human relationships. Our findings also showed that individuals with schizophrenia longed for marriage with someone who accepts them as they are to share a life together.

Our participants were trying not to think too much the past hospitalization but to strive for the current life. So they were aware of normal standing position in society. Individuals with schizophrenia who have maintained an active community life are considered to be on their way to recovery.

2. Effective care for community-dwelling individuals with schizophrenia who have experienced long-term hospitalization

Individuals with schizophrenia in this study were aware of distress but remained affirmative about their current life, and were actively involved in society so they could achieve their goal of creating a new life. It is essential for nurses to appreciate their thoughts and desires in daily life and to help achieve these goals with these individuals with schizophrenia. Katakura et al. (2007) have shown that home-visit nursing that promotes expression of intentions about the way they live or how to manage community life is a prerequisite for teaching life skills among individuals with schizophrenia who tend not to make their intentions clear due to past experience such as excessive interference by family members and long-term hospitalization²⁴. Therefore, it is essential to establish a nursing care system that emphasizes how to

express intentions before proposing a path to successful community life²⁴⁾.

In this study, individuals with schizophrenia acknowledged that one of the causes of the current difficulty of life is due to their mental disorders. To live in the community with colleagues in the workplace and/or neighborhood near the home, they needed to change themselves. The lack of flexibility would trigger off recurrence. It is also essential for individuals with schizophrenia to remain healthy to continue living in the community. There is a significant, although weak, correlation between clinical symptoms and social functioning²⁵⁾. It has been shown that home-visit nursing services for individuals with schizophrenia promote hospital visits and medication management, thus controlling symptoms and improving many aspects of social life such as diet and financial management²⁶⁾. Assessing current life skills²⁷⁾ and providing personalized support to individuals with schizophrenia empowers their lives and relationships with the surroundings, in addition to highlighting their personal power²⁸⁾. It is thought that nurses need to provide care that prioritizes the individual pace of persons with schizophrenia who come to terms with the condition²⁹⁾ and would like to regain the power to live by their own values and live an independent life with adequate disease control¹⁴⁾.

Nurses need to have skills to share present and past experiences, including hospitalization, with individuals with schizophrenia to remind them that they are responsible for their own path to recovery. It is necessary to understand their ambivalent thoughts, for example, “*wanting to escape from the negative situation*” and “*being admitted to hospital = assurance of security*.” Nurses support individuals not only focusing on their own weaknesses but also realizing the benefits gained in your life so far. When talking about life and disease, individuals with schizophrenia often use words with negative connotations such as anger and sorrow, instead of using positive terms; yet, this correlates with hopefulness³⁰⁾. Furthermore, the promotion of metacognitive talk to objectively perceive past

experiences facilitates recuperation among individuals with schizophrenia³¹⁾. Nurses need active listening skills when listening to stories in order to understand the context or entire storyline. To identify the intention of individuals with mental disorder toward community life, it is also important for nurses to understand the life experiences of persons with mental disorder and their personalities²⁴⁾. Accomplishing these make it possible to provide nursing care that supports the recovery process of individuals with schizophrenia who accept the disorder and intend to live by their own values, instead of encouraging them based the concept of recovery of healthcare professionals³²⁾.

Conclusion

The center of framework, that of subjective cognition about themselves and their life to date, in individuals with schizophrenia who had experienced long-term hospitalization in a psychiatric hospital and currently lived in the community, was “*learning from agonizing events to change oneself*.” It suggests that individuals with schizophrenia intend to change themselves through their various experiences during and after hospitalization.

Limitation of this study

The subjects of this study were individuals with schizophrenia receiving visiting care services or outpatient treatment. Therefore, the findings regarding subjective cognition among community-dwelling individuals with schizophrenia cannot be generalized. Therefore, to develop an effective care system for both patients and nurses in the future, we plan to investigate patients during the times when they most likely to require professional help to facilitate self-transformation, such as immediately after hospital discharge.

Acknowledgments

We thank the participants for sharing their personal stories and others for their help in this study. We also greatly appreciate Ms. Akiko Kawakita, Mushinkan, Kyoto, for helpful instruction.

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長期入院を経験し地域で暮らす統合失調症者の主観的認知の構造

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要 旨

本研究は、統合失調症者の地域生活を支援するため、精神科病院で長期入院を経験し現在は地域で暮らす彼らの、今までの自分自身および生活に対する主観的認知の構造を明らかにすることを目的とした。通算 3 年以上（継続 1 年以上を含む）入院し、現在は 1 年以上の地域生活を送る統合失調症者 8 名に約 30 分の半構造化面接を 3 回ずつ行った。面接内容は、KJ 法により 10 のグループ「島」に統合された。入院とは【理不尽な状態から抜け出したい】【病院＝守られる安心】【信仰に救いを求めて】といった、コントロール不能で無力感の強い状態であった。退院後は【過去に怯えない】【再入院しない闘い】といった、過去と距離を取りつつ、コントロールできる立ち位置を模索していた。地域生活では【結婚生活への憧れ】を秘めつつ、【社会的なポジションにおいて無理しない】【健常者との壁を越えたい】【普通の実感を励みに】といった、自分に合った居場所を希求する意識がみられた。【苦悩からも学び、自分を変えていく】ことで、入院中・退院後のさまざまな体験の意味を考え、自己を変容する姿勢がみられた。長期入院後に地域で暮らす統合失調症者に適切なケアを提供するためには、本人の人生を構成する過去の長期入院を含め、地域生活に関する現在の本人の見解を理解する必要がある。そして、主体的なコントロール感覚の獲得は彼らの課題であるため、統合失調症者本人のペースに合わせることも大切である。