

A Qualitative Study on What It Means for Patients with Schizophrenia Living in the Community to Remain on Medication

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Abstract

Background: Little is known about what the experience of “taking antipsychotics” means in a patient’s life. Therefore, this study aims to identify what it means for patients with schizophrenia living in the community to remain on medication. **Methods:** The participants were five residents of communities, who had been discharged from a psychiatric hospital, but were currently visiting a private psychiatric hospital. In this study, we used participants’ narratives as data and analyzed them according to the procedures described in “An Application of Phenomenological Method in Psychology” (Giorgi, 1975), and “Practice of analyzing materials describing experiences” (Giorgi, 2004). **Results:** The study results are as follows. 1) The drug may be effective, but Subject (below, S) still wants to take it as little as possible. Meanwhile, S has people who care about S and a person who S can rely on nearby, to manage S’s life. The people above tell S to take medicine, and S takes it. 2) S does not know what kind of medication S is consuming, but recently S has been having a hard time walking; S has people who care for S’s foot and look after S. S thinks taking medicine is for living. 3) S feel some drugs is ineffective. However, S met some people S could trust who passionately recommended the medication to S. S started being careful in remembering to take it. 4) S does not think drugs are necessary for S, but S can interact with people and spend S’s days. S has people who accept S as S is. S continues living in the community while taking medicine that a doctor offers. 5) S was skeptical about the drugs. However, S has a person S can trust, who recommended a way to take the medication in a way that S does not feel overwhelmed. S thinks that it may be a good idea to take it. **Conclusions:** Based on the analysis of the narratives of each of the five participants, the essential structure was read from the perspective of a third party regarding participants’ medication adherence. A generalized reading of the structure common to the above five essential

structures reveals a structure that includes the following three opportunities: 1) Patients realize the importance of people; 2) They sometimes entrust themselves to people or follow people's opinions when taking actions; 3) They have come to terms with their initial negative feelings about antipsychotic drugs, subsequently continuing to take antipsychotic drugs. This suggests that the following are important attitudes of supporters of patients with schizophrenia who continue to live in the community: To accept what is happening to the patients, to talk to them with encouragement and compassion, and to be there for them. It is also important for supporters to make patients feel comfortable in opening up while the patients reside in the community and to support patients in making decisions.

Keywords

Patients with Schizophrenia Living in the Community, Antipsychotic Drug, Narrative, Phenomenological Method

1. Introduction

According to the Ministry of Health, Labor, and Welfare's data's on mental health and social welfare (2019), as of 2017, the total number of patients with mental illness in Japan was approximately 4,193,000, of which about 302,000 were inpatients and 3,891,000 were outpatients. Among them, the number of patients with schizophrenia was 639,000, accounting for approximately 154,000 or 47% of the total number of inpatients, the largest proportion. As Japan has been implementing measures of mental health and social welfare to shift from a medical system centered on inpatient care to a system centered on community life of patients, the average length of hospital stay of patients with mental illness has decreased from approximately 301 days as of 2010 to approximately 266 days as of 2019 [1].

Nakane (2005) investigated the prognosis of patients with schizophrenia who were discharged and found that approximately 30% of the patients were discharged in remission from the hospital. Other patients were discharged with some residual psychiatric symptoms; while these were not in complete remission, they could still live in society [2]. The average number of days of patients' community life after discharge was approximately 307 days as of 2016, with readmission rates of 23% at 3 months' post-discharge, 30% at 6 months' post-discharge, and 37% at 12 months' post-discharge [1].

The figures above show an inconsistency in the recovery of patients discharged from the hospital and living in the community. Therefore, in the treatment and nursing care of schizophrenia, it is important to include help to patients to live their lives in the community while ensuring the prevention of the relapse of their symptoms.

According to the existing literature, it is extremely important for patients with schizophrenia to continue taking antipsychotic drugs to have a peaceful com-

munity life, because these drugs are effective in reducing positive symptoms and preventing relapse of symptoms. For this reason, health care providers implement practices to increase patients' compliance with antipsychotic drugs and knowledge of antipsychotic drug efficacy starting from patients' hospital stay period. The results of these practices have been widely reported, as shown below.

In a study by Shiotani *et al.* (2004), as a result of the abovementioned practices, eight of ten schizophrenia patients' anxiety regarding their medications had reduced, leading to their increased knowledge of medications; among these, two patients stated that "I only take it when I don't feel well" and that "it is poisonous to the body to take medicine for too long," respectively [3]. In a study by Ishida *et al.* (2008), 33 patients (86.8%) found the medication useful, and 23 patients (60.5%) stated that they would continue taking the medication after being discharged. Meanwhile, 14 patients (36.8%) thought that there were demerits from taking the medication, with thoughts such as "I do not take that because my disease is cured," "I want to try to see if I can be cured without taking it," and "You cannot say the condition becomes better when you are still taking medicines" [4]. Imai (2008) found that some patients with schizophrenia who were instructed to take their medications continued feeling ambivalent, stating "It seems that I will need the medications until I die, but I would stop taking them if I could" [5].

The previous studies mentioned above seem to suggest that some patients with schizophrenia continue taking antipsychotic drugs while having feeling mixed feelings about it, and do not easily accept medication adherence. The fact that schizophrenia patients "stay on medication" may not solely be the result of gaining illness awareness or of improving compliance with their medication, but may be the result of a process in which patients accept to continue taking antipsychotic drugs for various reasons as they carry on with their daily lives.

Therefore, we conducted a literature review to determine the findings of previous studies regarding the attitude/motivations of patients with schizophrenia when it comes to taking antipsychotic drugs. We found that patients with schizophrenia expressed their opinions in relation to "discontinuing medication," "resuming medication," and "becoming adherent to medication" [6]-[15]. The findings indicate that when it comes to consuming antipsychotic drugs, the patients investigated in different studies had the following in common, even though their backgrounds and circumstances differed: almost losing one's identity due to the side effects of the medication, discontinuing medication when they thought they had recovered, and feeling the need to take antipsychotic drugs upon readmission. Furthermore, patients with schizophrenia were found to be aware of and learning from the need for medication to maintain the relationships with the people they interacted with in the community.

However, little is known about what such patients' experience of "taking antipsychotic drugs" signifies in their lives, nor how they become adherent to antipsychotic drugs, which they could not do before.

Therefore, we believed that it would be important to analyze the narratives of

patients to understand what it signifies for them to consume antipsychotic drugs to continue living in the community.

2. Aims

This study aims to identify what it means for patients with schizophrenia living in the community to remain on medication.

3. Method

In this study, we used participants' narratives as data's and analyzed them according to the methods described in "An Application of Phenomenological Method in Psychology" (1975) [16] by Giorgi, an American phenomenological psychologist, and "Practice of analyzing materials describing experiences" (2004) [17]. Giorgi (1975) stated that the subjects' narratives contain their experiences and perceptions in their daily lives, as well as their backgrounds and circumstances. By analyzing these descriptions in the narratives, Giorgi (1975) attempted to clarify how the participants' awareness or their way of doing/being led to their making a decision [16].

We considered Giorgi's phenomenological method to be the most appropriate for this study, as it reveals participants' perception and the way of doing/being that was hidden and difficult to make explicit.

3.1. Participants

The selection criteria for participants were as follows:

- 1) A patient who could not continue taking antipsychotic drugs in the past and was admitted or readmitted to a psychiatric hospital, and has been ill for more than 10 years.

- 2) A patient who received inpatient treatment in the past is currently encouraged to continue taking the medication during regular outpatient visits, and has been taking the medication on their own volition for at least 1 year.

- 3) A patient with schizophrenia from early adulthood to late adulthood (around 30 to 55 years of age) who has been taking antipsychotic drugs with chlorpromazine equivalent of 500 mg to 1200 mg and has managed to live in the community for at least 1 year.

- 4) A patient with schizophrenia who has been determined by the attending doctor to be able to recount their own experiences related to taking antipsychotic drugs.

Patients in (5) and (6) below are excluded from participants.

- 5) A patient whose attending doctor is concerned that the patient talking about their own experiences related to antipsychotic drugs may worsen their mental condition.

- 6) A patient who has been determined to have insufficient decision-making capacity in narrating their story, or a patient with the hebephrenic type of schizophrenia, which is considered to develop during the ego formation period around the age of 16.

3.2. Data Collection Method

Interview dates, times, and locations requested by the participants were identified and decided upon after coordinated communication. Interviews were conducted in locations where privacy was ensured. At the beginning of the interview, the participants were first asked to complete a form including sociodemographic attributes, such as gender and age. The interviews were recorded on an IC recorder and written in memos with the participants' consent. Semi-structured interviews were conducted. While the researchers prepared a list of questions, they also asked additional questions based on the flow of the conversation. Each participant's interview was scheduled for approximately 40 minutes. When the interview seemed to exceed the scheduled time, the participant was asked whether it would be acceptable to extend the time originally agreed upon by them.

The participants were first asked to talk about their community life freely; subsequently, the interview gradually included the following questions to draw out their narratives related to medication in their daily life experiences: 1) "How do you feel about the difficulties in your life?" 2) "Do you feel you have someone who supports you?" or 3) "You continue taking medication now. Did you have any episode that led you to continue taking medication?"

3.3. Analysis Methodology

In this study, we used participants' narratives as data's and analyzed them according to the procedures described in "An Application of Phenomenological Method in Psychology" (Giorgi, 1975) [16], and "Practice of analyzing materials describing experiences" (2004) [17]. Throughout the entire analysis process, the researchers—currently working as faculty in mental health and psychiatric nursing—focused on the participants' narratives, ensuring to exert conscious efforts to include as few biases as possible in interpreting the narratives (Giorgi, 1975) [16].

The following steps were undertaken in the analysis; the analysis was performed for each participant.

1) Step 1

Transcriptions (hereinafter referred to as "source materials") were prepared from the participants' narratives. Original texts were read through several times to grasp the overall meaning of the source materials. Subsequently, the source materials were read through again from the beginning, and the contents were categorized by semantic cohesion to construct semantic units.

2) Step 2

Among the constructed semantic units, only the units that were related to the participants' medication adherence were retained.

3) Step 3

For each semantic unit constructed in Step 2, subjects were rewritten as a neutralized subject "S" (the initial of Subject), reflecting the participants' changes in

thoughts. This step changes original semantic units per the intentions on the left, which is called free imaginative variation (Giorgi, 2004) [17].

4) Step 4

After the free imaginative variation was conducted on each description in Step 3, the psychological meaning related to “what it means for patients with schizophrenia living in the community to remain on medication” was read for each semantic unit. Semantic units that could not be read were left as they were, stopping the analysis procedure at the stage of free imaginative variation.

5) Step 5

Each psychological meaning by semantic unit read in Step 4 was arrayed in a chronological order.

6) Step 6

The psychological meanings arrayed in Step 5 were repeatedly read to grasp the entire meaning, to read what the third party will discern regarding the participants’ medication adherence as the essential structure.

4. Definition of Terms

Psychological meaning: A person’s awareness or behavior that is important to that person in forming the new way of doing/being in that individual’s journey, as read by researcher.

Essential structure: The mechanism by which diverse psychological meanings for the person overlap, to make it possible for them to continue taking the medication.

5. Ensuring Reliability and Validity

It was important for this study to be as faithful as possible to the facts of the participants’ narratives to clarify what really occurs, without being constrained by the researchers’ subjectivity or bias. To this end, the process of analysis from Steps 1-6 was conducted by repeatedly reviewing the source materials and the converted data’s, and by proceeding step by step under the supervision of a researcher specializing in mental health and psychiatric nursing, in an effort to avoid arbitrary bias in the interpretation.

6. Ethical Considerations

The human material or human data were performed in accordance with the Declaration of Helsinki. The study was commenced with the approval of Osaka Medical and Pharmaceutical University Ethics Review Committee (No. 2020-236-2).

6.1. Participants

The participants were residents of communities, who had been discharged from a psychiatric hospital, but were currently visiting a private psychiatric hospital. Their consent for their participation in the study was obtained from themselves, their attending doctors, and the hospital directors.

6.2. Discretion to Participate in the Study and Withdrawal of Consent to Participate in the Study

The participants were informed that their participation would be voluntary, that they were free to reject to participate or withdraw from the study at any time, and that participating in the study would not affect their treatment or care they receive in any way, or impact their relationship with the hospitals in any way.

6.3. Privacy Protection

The participants were informed that their personal information obtained in the course of this study would be protected, that the study data's would be compiled in a generalized form that would not identify any particular individual, and that their anonymity would be maintained, including in the study products.

6.4. Protection of Personal Information

Raw data's acquired using IC recorders were stored securely in a locked cabinet in a graduate student's office in the facility of the researchers' affiliated university. A lockable room was used to facilitate the transcription. All proper nouns in all materials and data's related to the study were anonymized and pseudonymized by replacing them with initials and unrelated alphabetic characters such that individuals could not be identified. After publishing the study, the digitized data's will be stored for 10 years after organizing and managing the dates and metadata's and creating appropriate backups. Paper materials will also be stored for 10 years. After 10 years of storage, paper and other data's and materials will be shredded, and USB and other electronic media will be crushed and then discarded.

7. Results

Among the five participants (A, B, C, D, E), the longest narrative interview lasted for approximately 44 minutes, and the shortest for roughly 18 minutes; the average narrative interview period was approximately 31 minutes (**Table 1**).

Table 1. Summary of participants.

Participant	Gender	Age	Main illness	Living with family or not	Time of interview	Duration of living in the community
Ms. A	female	Early 50's	schizophrenia	living alone. Family lives nearby.	24 min. 53 sec.	Between 3 and 4 years
Mr. B	male	Late 60's	schizophrenia	Lives with mother	16 min. 44 sec.	More than 10 years
Mr. C	male	Early 30's	schizophrenia	living alone. Family lives nearby.	24 min 23 sec.	More than 2 years
Mr. D	male	Early 60's	schizophrenia	Live alone.	18 min 49 sec.	Between 7 and 8 years
Mr. E	male	Early 40's	schizophrenia	living alone. Family lives nearby.	17 min 50 sec.	More than 10 years

Figure 1-5 show the process of analysis for each of the above participants to read the psychological meaning and essential structure of their medication adherence to continue their community life from their narratives. The first column includes the description of each semantic unit that was discussed in relation to their medication adherence. The second column includes the description of free imaginative variation, which was structured into contents that showed their changes in thoughts by changing the subjects to neutralized subjects for each semantic unit. The third column includes the description of the psychological meanings read from the description of free imaginative variation. The fourth column includes the chronologically arrayed description of the above-mentioned psychological meanings. The final fifth column shows the essential structure of the mechanism that makes the participants' medication adherence possible, which is visible to the third party from the overall psychological meanings arrayed in the chronological order.

7.1. Psychological Meaning and Essential Structure of Participant A to Continue Taking Medication to Continue Living in the Community

The following is a chronological sequence of psychological meaning read from Participant A's narrative: 1) "When Subject (below, S) was initially prescribed the drug, S thought S should not take it." 2) "These days, S does not think people are coming to kill S anymore." 3) "S still does not want to take drugs if possible." 4) "S's doctor has told S that it is impossible to reduce S's medication any further." 5) "S's family is telling S that S needs to take S medicine." 6) "S feels that S has someone who cares about S, such as the home care nurse." 7) "S's sister manages most of S current daily life."

From the entirety of 1) to 7) above, the essential structure of Participant A to continue taking medication could be read as follows: "The drug may be effective, but S still wants to take it as little as possible. Meanwhile, S has people who care about S and a person who S can rely on nearby, to manage S's life. The people above tell S to take medicine, and S takes it (**Figure 1**)."

7.2. Psychological Meaning and Essential Structure of Participant B to Continue Taking Medication to Continue Living in the Community

The following is a chronological sequence of psychological meaning read from Participant B's narrative: 1) "S finds it hard to walk these days." 2) "S feels that S has a doctor who cares about S's condition of foot." 3) "S has a mother who takes care of S and recommends a way for S to take the drugs." 4) "S does not know what medications S is taking right now." 5) "S says, taking medicine is for living."

From the entirety of 1) to 5) above, the essential structure of Participant B to continue taking medication could be read as follows: "S does not know what kind of medication S is consuming, but recently S has been having a hard time walking; S has people who care for S's foot and look after S. S thinks taking medicine is for living (**Figure 2**)."

Semantic unit	Free imaginative variation	Intuited psychological meaning	Time series-based array of psychological meaning	Essential structure intuited from the time series-based array
I have a younger sister. She lives kind of close by, about 20 minutes by car. My sister manages most of my day-to-day life. Living expenses, utilities bills... My sister manages all the money I need for day-to-day living. Yeah, it's easy. Yes, even with city hall matters, my sister takes care of things, and so that's why I have the life I have now.	Subject (below, S) says that although they live alone, having their sister living nearby makes them feel safe and not alone. In addition, they said that being able to discuss it with their younger sister when something happens, the sister managing the money needed for daily life, and dealing with city hall matters are a relief. They are grateful to their sister for their current lifestyle.	S's sister manages most of S's life now.	When S was first prescribed the medication, S did not think S should take it. Recently, S has stopped thinking that people are coming to kill S. S still doesn't want to take any medication, if possible. Doctors tell S that S cannot reduce the dosage of the medication further. S is under pressure because S's family constantly tells S that S needs to take the medication. The visiting nurses not only check whether S is taking S's medicine, but they also take care to ask S to talk freely and discuss things with them.	The drug may be effective, but S still wants to take it as little as possible. Meanwhile, S has people who care about S and a person who S can rely on nearby, to manage S's life. The people above tell S to take medicine, and S takes it.
Researcher: (Do you know what kind of medications you are taking now?) I take the medicine I'm given, so I don't know what's in it. At first, I didn't want to take it. I know someone with terrible depression. They were seeing a psychiatrist...They couldn't sleep without it, so I didn't want to be like that. At first, when I was given medicine for this kind of illness, I thought that taking it would be really bad.	S says they are taking the prescribed medication and that they do not know what it is. S also says that when first prescribed the medication, they were strongly opposed to taking it because they did not want to become like their friend with depression who is unable to sleep unmedicated.	When S was first prescribed the medication, S did not think S should take it.		
At first, when the doctor told me nothing was coming to kill me, I couldn't believe it. Um, I don't know when. As the days went by I didn't know if the medication was working. (Recently) I've come to realize that it (people coming to kill me) is ridiculous.	S says that at first, they were unable to believe the doctor when told that no one was coming to kill them. However, with the passage of time, S began to think it ridiculous, although they do not know whether or not this is due to the medicine.	Recently, S has stopped thinking that people are coming to kill S.		
My mouth and tongue started to move, like this, for a while. I also take sleeping pills to sleep. But they work so well that I can't wake up, and I'm wetting the bed. You can't wake up... If you take that medication, you can't wake up. I didn't want to be given them. I wanted the amount to be reduced. I said that, but it's not possible. So, since the medication is necessary for my illness, the amount can't be reduced. I was told that all they could do was increase the medication that suppresses the side-effects.	S described a brief protrusion of the tongue as well as urinary incontinence due to the strong effect of sleeping pills. S told the doctor in charge at the time that they wanted the dosage reduced, but their doctor told them that because the dosage prescribed was the dosage necessary for their illness, it could not be reduced. Consequently, medication to suppress side effects had to be increased, though S had wanted to reduce the amount of medication they were taking.	Doctors tell S that S cannot reduce the dosage of the medication further.		S's sister manages most of S's life now.
Yes, because I am told by my family and those around me that I should take it. Yes, I feel the pressure (with a wry smile). I am told not to just stop taking the medication on my own, no matter what. Yes, by my sister. She's hard on me (smiling wryly).	S says they feel pressure because their family frequently tells them that they must take their medication. They also say that their sister has told them never to stop taking the medication on their own.	S is under pressure because S's family constantly tells S that S needs to take the medication.		
A visiting nurse comes and checks the medication. That's one of the reasons. Yes. And to give advice. During this time of year, around April and May, things get a little bad. So, how can we prevent it? Warning me in advance, those kinds of discussions. The same goes for auditory hallucinations and even things that happen in my daily life. The nurse says that if anything happens, just to please talk to them about it. Just having someone to talk to makes a difference.	S reports that visiting nurse comes around to check their medication, help when things get bad, talk about auditory hallucinations, and discuss anything S needs to. S says that just having someone to talk to makes a difference.	The visiting nurses not only check whether S is taking S's medicine, but they also take care to ask S to talk freely and discuss things with them.		
What about your medication? I don't want to take it, if possible. Yes. I wonder if there is a way to cure it without medication. Yes. People around me tell me to take it, so just take it (wry smile).	S says they really don't want to take the medicine, if possible, but they have no choice because the people around them tell them they must. And, S says that they wonder if a non-medication cure is available.	S wonder if there is a way to cure this without medication.		

Figure 1. The psychological meaning and essential structure of research participant A continuing to take medication in order to continue living in the community.

Semantic unit	Free imaginative variation	Intuited psychological meaning	Time series-based array of intuited psychological meaning	Essential structure intuited from the time series-based array
<p>Researcher: (Living in the community, spending your days like this, etc.) Because I have parents. I'm not very particular about it, I'm not. Researcher: (Oh, is that so? How do you get a long with your mother?) We get along well.</p>	(S) says that he lives with his mother and is not very particular about his day-to-day life.		<p>Lately, walking is tiring.</p> <p>S has a doctor who cares about S, with S's poor legs.</p> <p>S has S's mother who looks after S and tells S to take S's medications separately.</p> <p>S does not know what kind of medication S is taking now.</p>	S does not know what kind of medication S is consuming, but recently S has been having a hard time walking; S has people who care for S's foot and look after S. S thinks taking medicine is for living.
<p>Researcher: (B, have you ever wanted to stop taking your medication?) No Yeah, well... I'm running out of medicine...I have to take it. Researcher: (Do you know what medications you are taking now?) I don't know.</p>	(S) says he thinks he has to take his medication, and he has never thought about stopping. (S) says he does not know what kind of antipsychotic he is currently taking.	S does not know what kind of medication S is taking now.	<p>S has a doctor who cares about S, with S's poor legs.</p> <p>Taking medication is something you do in order to live.</p>	
<p>Researcher: (You are taking medication from your regular doctor.) (Nods twice.) Be careful, you might fall over if you take this kind of medicine. Researcher: (At your doctor's appointment your regular doctor says, "You must keep taking this," or "It's dangerous not to.") Yes (nodding).</p>	(S) says his doctor warns him that he is at risk for falls when taking the medication.	S has a doctor who cares about S, with S's poor legs.		
<p>Researcher: (Do you have any kind of aid, or circumstances, or people who support you to keep taking your medication?) A parent. Researcher: (Oh, a parent. Could you share what kind of conversations you have?) They tell me to take each medicine separately. Researcher: (So that is how your mother talks to you, B?) (An emphatic nod).</p>	(S) says that his mother tells him to take each medicine separately.	S has a mother who looks after S and tells S to take S's medications separately.		
<p>Researcher: (What does the medication you are taking mean to you, B?) It is something you do in order to live. (Speaks each word slowly, one at a time). Researcher: (In order to live.) (Nodding slowly). Researcher: (You mean it's very important.) Yeah. Researcher: (Do you know how long you've felt that way?) Um... (Smiles wryly, then tilts head to look at the researcher). Researcher: (So, before you realized it, it became something that you do in order to live.) Yeah.</p>	(S) says that for him, taking medication is something done in order to live.	Taking medication is something you do in order to live.		
<p>Researcher: (Have you ever wished for things to be different?) It's far to the pharmacy, so I want to do something about that. Far away. Since I have this. (Taps the floor with their cane.) Researcher: (Oh, since you walk with a cane.) Yes (for about 3 seconds). It's tiring. It would be nice if there was a pharmacy in the hospital. Researcher: (If you are going to continue to walk, it would be better if it was closer.) Yeah.</p>	Since (S) uses a cane and the walk to the pharmacy is far, he wishes that something could be done to improve that. He said it would be good if there was a pharmacy in the hospital.	Lately, walking is tiring.		

Figure 2. The psychological meaning and essential structure of research participant B continuing to take medication in order to continue living in the community.

Semantic unit	Free imaginative variation	Intuited psychological meaning	Time series-based array of the intuited psychological meaning	Essential structure intuited from the time series-based array
Since six months ago ... Umm, it seems like my body is not my body. I felt like I was being taken over by something. Um, yeah. It was about five years ago. It was very hard. In the early days, I would hear things. And I felt like I was being swayed by the auditory hallucinations...like, (in my head) someone came in (there was a gesture of holding the top of the head and turning it around), and I felt like I was being spoken to, and there was not just one. Yeah, being affected by the auditory hallucinations was the hardest thing.	(S) describes their situation six months ago, when they felt as if their body had been taken over by something. (S) says that experiencing auditory hallucinations five years ago was the most difficult thing and that in the beginning they felt like they were being swayed by those hallucinations. (S) says that there was a sense of someone entering their head and talking to them. (S) said that being influenced by auditory hallucinations was the hardest thing.		At first, S could not feel the effects of the medication. Symptoms occur when S does not take the medication, and S thinks that if S does not take it properly, things will be bad. The doctor recommended taking the medication, since otherwise, the symptoms could worsen.	S feel some drugs is ineffective. However, S met some people S could trust who passionately recommended the medication to S. S started being careful in remembering to take it.
Researcher: (Did you feel the effect of the drug when you were taking it?) At first, I didn't realize it, but then I became aware that things had gradually calmed down.	(S) says that although they did not feel the effect of the medication initially, they later felt that things had gradually settled down.	At first, S could not feel the effects of the medication.		
I thought that if my symptoms subsided even a little, I should listen to my doctor and continue taking the medication. That was the situation, yes. I've been told continually (by my doctor) that I should definitely take the medication and that my symptoms could worsen again (otherwise). Yes, I felt like I definitely (said with emphasis) have to take the medication. It was like, they were desperate for my sake...yeah.	(S) described a situation wherein they considered it best to listen to the doctor and continue to take medication, even if the symptoms subsided only slightly. (S) felt that the doctor was desperate for them to continue the medication, imploring "I definitely want you to take the medication."	The doctor recommended taking the medication, since otherwise, the symptoms could worsen.	There are times when S does not feel the effect of the medication, but S has to keep taking it for as long as the doctor says to. S takes care not to forget to take S's medication, and S uses a kind of medication calendar.	
Researcher: (How often do you see your doctor?) Twice a month. Today, I felt like I had to go to see the doctor again today. It felt like my appointment day was finally here, hahaha (wry smile). Researcher: (How do you feel at the end of your appointment?) I'm relieved. I finished my appointment and got some medication. I feel relieved when I have medication.	(S) reports feeling nervous on appointment day but relieved when the appointment is over and the prescribed medication is at hand.			
After I got schizophrenia, um, what should I say about that one time... I went to appointments at the hospital for a month or two after I was discharged. Then, I quit going to the hospital. I thought it would be okay. I don't know what to say. I got symptoms again. I went back to needing the hospital again. That's it. I wondered if things would be bad if I didn't take the medication (a pause of about 3 seconds), yeah. And I thought that if I stopped taking medication, it would be like before.	(S) reports that they continued outpatient appointments at a psychiatric hospital for a month or two after being discharged. (S) stopped taking the medicine once, thinking, "it will be fine now," but symptoms began to appear again, and they were admitted to the hospital. (S) says that at the time they "wondered if things would be bad if (they) didn't take the medication properly" and that if they stopped taking medication, it would be like before.	Symptoms occur when S does not take the medication, and S thinks that if S does not take it properly, things will be bad.		
Researcher: (I think you are now being administered depot injections. So, what does the depot injection mean to you?) At the moment, I sometimes wonder if there is any point. I don't really feel anything. Even if it gets worse than this, it is what it is. I continue to feel I should listen to what the doctor says. Yeah, I came to realize that I should not quit my medication after all. I suppose I have to keep taking it until the doctor says I can quit.	(S) is using depot injections and has not felt the effect of the depot medication as yet, but they think it meaningful to continue taking it. (S) says that even if things get worse, "it is what it is," and will continue to take the injections, thinking that they should listen to the doctor's advice. (S) says that they have come to realize that they should not quit the medication and should continue taking it until the doctor says it is okay to stop.	There are times when S does not feel the effect of the medication, but S has to keep taking it for as long as the doctor says to.		
Researcher: (Is there anything in your life that you are taking care in doing?) Yes. Well, I am being careful to take my medicine. Yes. And I have a sort of medication calendar. I put medication inside (the correct square), and then I take it. The calendar has Monday through Sunday written on it. I put the medication in it and try not to forget to take it.	(S) uses a medication calendar to ensure they do not forget to take the antipsychotic medication.	S takes care not to forget to take S's medication, and S uses a kind of medication calendar.		

Figure 3. The psychological meaning and essential structure of research participant C continuing to take medication in order to continue living in the community.

Semantic unit	Free imaginative variation	Intuited psychological meaning	Times series-based array of intuited psychological meaning	Essential structure intuited from the time series-based array
<p>Researcher: (I would like you to talk about your thoughts regarding living in the community.) I'm busy with household chores. Yes, I cook. Every day. Hmm, I wonder how many years it is? Maybe seven or eight years. I think it's been seven or eight years now.</p> <p>Researcher: (So, do you feel like your life is stable now?) I have a headache. I worry that I won't be able to do my own things because I'm busy with household chores. I'm in a situation where I can't do it because my head is a little painful, but when my headaches are cured, I want to study to become a songwriter. Yes, that's right. I want to be a songwriter who writes lyrics. I want to be a songwriter, not a singer.</p>	<p>(S) has been living in the community for seven to eight years, cooking daily, but has headaches and is concerned that they will be unable to do the things they want to due to being busy with household chores. (S) wants to study to become a lyricist when their headaches are cured.</p>	<p>S has been living in the community for several years, doing S's own household chores every day.</p>	<p>S has been living in the community for several years, doing S's own household chores every day.</p> <p>S was able to interact with other people at the adult day care service, so it became easy to spend time there.</p> <p>S does not think S needs antipsychotics.</p> <p>Talking with visiting nurses about S's own daily life, such as whether S has gone somewhere, whether S is handling the housework, and so on, is an encouragement for S's to continue on with S's day-to-day life.</p> <p>S takes the medication prescribed by the doctor, thinking that it cannot be helped.</p>	<p>S does not think drugs are necessary for S, but S can interact with people and spend S's days. S has people who accept S as S is. S continues living in the community while taking medicine that a doctor offers.</p>
<p>Researcher: (Was there something that happened to make you think that you should try taking the medication? Was there anything like that?) They give it to me, so I take it. It can't be helped (with a slightly wry smile).</p> <p>Researcher: (You are currently taking medication. Did anything happen to make you want to continue taking it?) No, not really. They give it to me, so I take it. Well, I would say that it is the same as usual, but (pauses for about 12 seconds) there was no specific explanation about the medication.</p>	<p>(S) smiles slightly wryly as they say that they take medication because it is given to them (by the doctor). They say that it cannot be helped. (S) also says that they never wanted to take medication; rather, they take it because the doctor prescribes it.</p>	<p>S takes the medication prescribed by the doctor, thinking that it cannot be helped.</p>	<p>S takes the medication prescribed by the doctor, thinking that it cannot be helped.</p>	
<p>Researcher: (Do you have any memorable moments?) (Looks down and frowns for about five seconds.) Hmm, I forget.</p> <p>Researcher: (I wonder if something might have happened.) Hmm, yeah, probably. I don't remember much.</p> <p>Researcher: (You go to an adult day service. How is that?) I don't know, I guess it's easy to spend time there. Hmm, I can interact with other people.</p>	<p>When asked about memorable moments from conversations with their doctor or others, (S) says that, despite trying for a while to recall, they do not remember much or have forgotten. They say that it is probably easy for them to spend time at the adult day care service because they are able to interact with other people.</p>	<p>S was able to interact with other people at the adult day care service, so it became easy to spend time there.</p>		
<p>Researcher: (What do you think about the medication you are currently taking?) Oh, I'm not very happy. But, there are also medications to lower blood pressure and to eliminate constipation. I need those, but I don't think I need medication for mental illness. When you take the medication, it's not bad, really.</p>	<p>(S) states that they need medications to lower their blood pressure and treat their constipation but that they are not very happy about the antipsychotics and do not think they are necessary.</p>	<p>S does not think S needs antipsychotics.</p>		
<p>Researcher: (Do you have any painful symptoms in your day-to-day life?) I have headaches, constipation, and high blood pressure. Yes. I take medication to lower my blood pressure and for constipation. Umm (pauses for about 4 seconds), I am getting rid of (the symptoms) in order (of painfulness).</p>	<p>(S) states that they are suffering from headaches, constipation, and high blood pressure and that they take medications to lower blood pressure and improve constipation. They said they are eliminating the symptoms in order of painfulness.</p>			
<p>Researcher: (Do you know how you want to live your life?) I want to be a professional lyricist. I want to be able to make a living writing lyrics.</p> <p>Researcher: (Do you have anyone who listens to you or supports you when you talk about wanting to be a lyricist?) The visiting nurses, I guess. Like, have you gone anywhere in the past week? Are you managing to do the housework? We talk about day-to-day life. It is encouraging to talk of such things. Yes. It is encouraging in my daily life.</p>	<p>(S) spoke of wanting to become a professional lyricist and to make a living writing lyrics. (S) says that talking to the visiting nurse about activities that week and the status of the housework encourages them in their daily life.</p>	<p>Talking with visiting nurses about S's own daily life, such as whether S has gone somewhere, whether S is handling the housework, and so on, is an encouragement for S's to continue on with S's day-to-day life.</p>		

Figure 4. The psychological meaning and essential structure of research participant D continuing to take medication in order to continue living in the community.

Semantic unit	Free imaginative variation	Intuited psychological meaning	Time series-based array of intuited psychological meaning	Essential structure intuited from the time series-based
<p>It was hard when this disease appeared. I didn't even know about schizophrenia, so I was like, do I really have it? Now, in hindsight I think I really have it. At that time, I could really hear (my hallucinations). I really thought I was being chased by a group of stalkers. I felt very stressed about that kind of harassment.</p> <p>Researcher: (Do you remember what made you go to the hospital at the time?) Um, well, my family, of course. Family. They said that if it was so terrible, I had better to go talk to them at the hospital. At that time, I didn't know anything about the disease at all. After my family said that, I felt like, at first, that I had no choice but to go to the psychiatric hospital.</p>	<p>Before they knew anything about schizophrenia, (S) believed they were being pursued by a group of stalkers. They also talked about how stressful it was to hear the voices of the stalkers and to think that they were being secretly recorded, visually and aurally.</p> <p>(S) recalled that they knew nothing about the disease (schizophrenia) at the time, but after their family insisted it would be best, they felt they had no option but to go to a psychiatric hospital for the first time.</p>		<p>At first, S was doubtful about the effects of the medicine.</p> <p>Once, S stopped taking medicine because S thought it was healed. S reverted back to S's previous state, and S realized that S could not stop taking the medication.</p> <p>When S was still doubtful about the medication, S's mother told S that it would be a godsend if it cured S.</p>	<p>S was skeptical about the drugs. However, S has a person S can trust, who recommended a way to take the medication in a way that S does not feel overwhelmed. S thinks that it may be a good idea to take it</p>
<p>Yeah. Medication... Yeah I wondered if it would have any effect, if I even took it. Yeah, I was sceptical. I wondered if something like this would actually heal me. Because in my mind I thought (the hallucinations) were really happening. At first, I thought the medication would be useless.</p>	<p>(S) says that they were doubtful about whether the drug was useful because they really believed they were being harassed by a group of mass stalkers.</p>	<p>At first, S was doubtful about the effects of the medicine.</p>	<p>S felt anxious that if S stopped taking the medicine, S would return to S's previous state.</p>	
<p>Researcher: (Are there any memorable happenings or events that you think are thanks to the medication?)</p> <p>Well, yes. Because the pain and headaches are gone. And I feel a decrease in my stress. Also though, things are a little different due to the side effects. For instance, if I stop taking my current medication, I am a bit worried I will return to my previous state.</p>	<p>(S) recounted being worried that if they stopped taking the medication, they would revert to a state wherein they were experiencing constant auditory hallucinations.</p>	<p>S felt anxious that if S stopped taking the medicine, S would return to S's previous state.</p>	<p>S thinks it would be great if taking the medication cured S.</p>	
<p>Researcher: (Did something happen to make you continue taking your medication?)</p> <p>Umm. (Pauses for about two seconds) Oh, once, I thought I was cured, so I stopped taking the medication. A while after I stopped, the same thing happened again. At that time, I realized I actually had schizophrenia. So I thought, "I cannot stop taking the medication."</p>	<p>(S) recalled having stopped taking medication once in the past because they thought they were healed. After a while, when (S) reverted to the same condition, it was then that (S) realized that they are definitely schizophrenic and thought they could not stop taking the medication.</p>	<p>Once, S stopped taking medicine because S thought it was healed. S reverted back to S's previous state, and S realized that S could not stop taking the medication.</p>		
<p>Researcher: (I don't know if you'd call it support, but were there any words or events that left an impression on you?)</p> <p>Oh, my family. Yes, I was doubtful about taking medication. It was my mother telling me that if taking medicine healed the disease, it would be a godsend.</p>	<p>(S) doubted the medication's effectiveness, but their mother's words, "If taking the medicine healed you, it would be a godsend," left an impression.</p>	<p>When S was still doubtful about the medication, S's mother told S that it would be a godsend if it cured S.</p>		
<p>Researcher: (Are there any things you want to do in the future?)</p> <p>Hmm, well, it's hard to say. When I'm motivated and have willpower, I want to do my best. I wonder if medication could help in this area.</p>	<p>(S) says that when motivated, they want to do their best.</p> <p>(S) states that it would be nice if the medication was effective at improving motivation.</p>			
<p>Well, I think that mentally, thinking of the medicine as a godsend is important if continuing to take it cures you. In my case, the push from my family played a big part. I thought it would be great if taking the medication cured me, because there were times when I didn't like taking it. Having my family say that was huge.</p>	<p>(S) expressed the idea that when taking medication, it is mentally important to think of that medication as a godsend if it cures them.</p> <p>(S) stated that there was a time when they disliked taking medication, but their family's push, that is saying, "Wouldn't it be great if taking antipsychotics healed you?" impacted them greatly.</p>	<p>S thinks it would be great if taking the medication cured S.</p>		

Figure 5. The psychological meaning and essential structure of research participant E continuing to take medication in order to continue living in the community.

7.3. Psychological Meaning and Essential Structure of Participant C to Continue Taking Medication to Continue Living in the Community

The following is a chronological sequence of psychological meaning read from Participant C's narrative: 1) "In the beginning, S did not feel the effects of the drugs." 2) "When S did not use the medicine, the symptoms came back. S thinks it is bad if S does not take medicine properly." 3) "S met a doctor who passionately recommended taking medication." 4) "S does not feel some of the medications are effective, but S thinks S needs to keep taking them until the doctor says S can stop." 5) "S continues seeing a doctor in charge and taking antipsychotic drugs, to ensure that S does not forget to take medications."

From the entirety of 1) to 5) above, the essential structure of Participant C to continue taking medication could be read as follows: "S feel some drugs is ineffective. However, S met some people S could trust who passionately recommended the medication to S. S started being careful in remembering to take it (Figure 3)."

7.4. Psychological Meaning and Essential Structure of Participant D to Continue Taking Medication to Continue Living in the Community

The following is a chronological sequence of psychological meaning read from Participant D's narrative: 1) "S has been living in the community for several years, doing S's own chores every day." 2) "It is easier to spend time at the day care center now that S can interact with other people." 3) "S does not think antipsychotic drugs are necessary for S." 4) "Talking with the home care nurse about S's life, whether S has gone out somewhere or whether S has done S's chores, encourages S to continue with S's daily life." 5) "S takes the medicine because the doctor offers it to S; S thinks S has no choice but to take the medicine."

From the entirety of 1) to 5) above, the essential structure of Participant D to continue taking medication could be read as follows: "S does not think drugs are necessary for S, but S can interact with people and spend S's days. S has people who accept S as S is. S continues living in the community while taking medicine that a doctor offers (Figure 4)."

7.5. Psychological Meaning and Essential Structure of Participant E to Continue Taking Medication to Continue Living in the Community

The following is a chronological sequence of psychological meaning read from Participant E's narrative: 1) "At first S was skeptical about the drug's effectiveness." 2) "Once S thought S recovered and stopped the medication, S had the same symptoms as before; hence, S figured S could not stop the medication." 3) "S was still skeptical about the effectiveness of the medicine, but S's mother told S to take it anyway as it would be lucky if S got well." 4) "S felt anxious because if S stopped taking the medication, S might return to S's old condition." 5) "S

thinks that it will be a lucky thing if S just takes the medicine and get well.”

From the entirety of 1) to 5) above, the essential structure of Participant E to continue medication could be read as follows: “S was skeptical about the drugs. However, S has a person S can trust, who recommended a way to take the medication in a way that S does not feel overwhelmed. S thinks that it may be a good idea to take it (Figure 5).”

8. Discussion

Through the involvement with people who “manage,” “care about,” “care for,” “accept,” “passionately recommend,” and “recommend a way to take the medication such that S does not feel overwhelmed,” the participants showed a change in their thoughts.

Generalized reading of the structure common to the aforementioned five essential structures reveals a structure that includes the following three opportunities: 1) Patients realize the importance of people. 2) They sometimes entrust themselves to people or follow the opinions of these people regarding taking actions. 3) They have come to terms with their initial negative feelings about antipsychotic drugs and, since then, have continued taking antipsychotic drugs (Figure 6).

In the following section, we discuss patients with schizophrenia living in the community continually taking medication for each of the above three opportunities: 1) “feeling the importance of people in the community,” 2) “the willingness to entrust themselves to people and to let these people’s opinions guide them in making actions,” and 3) “coming to terms with negative feelings about antipsychotic drugs.”


Research participant A	Research participant B	Research participant C	Research participant D	Research participant E
The drug may be effective, but S still wants to take it as little as possible. Meanwhile, S has people who care about S and a person who S can rely on nearby, to manage S’s life. The people above tell S to take medicine, and S takes it.	S does not know what kind of medication S is consuming, but recently S has been having a hard time walking; S has people who care for S’s foot and look after S. S thinks taking medicine is for living.	S feel some drugs is ineffective. However, S met some people S could trust who passionately recommended the medication to S. S started being careful in remembering to take it.	S does not think drugs are necessary for S, but S can interact with people and spend S’s days. S has people who accept S as S is. S continues living in the community while taking medicine that a doctor offers.	S was skeptical about the drugs. However, S has a person S can trust, who recommended a way to take the medication in a way that S does not feel overwhelmed. S thinks that it may be a good idea to take it.
<p>The general structure that can be intuited from the intuited structure of the five cases above is as follows:</p>  <p>The patient is aware of the importance of others, and in entrusting their fate to others or relying on the opinions of others at times, they were able to reconcile initial negative feelings about antipsychotic medication, and they continue to take it.</p>				

Figure 6. Five essential structures and their generalizations.

8.1. Feeling the Importance of People in the Community

Why do participants who continue living in the community talk about people who care about them as close, reliable, and trustworthy?

In a study of people with schizophrenia who experienced auditory hallucinations living in the community, Ninomiya *et al.* (2005) found that some people were healed by having someone they could trust to understand their feelings, such as “I was healed by a friend who noticed my pain,” and that the presence of people itself provided emotional support and helped them to lead mentally stable lives [18]. Okamoto (2020) suggested that recovery might be facilitated by schizophrenia patients’ perception of emotional support from people, including professionals of mental health and social welfare and social relationships [19].

From the perspective of these previous studies, the experience of feeling the care, concern, and acceptance from people may encourage participants to continue their community life and feel secure knowing that they are being looked after.

8.2. Their Willingness to Entrust Themselves to People and to Let People’s Opinions Guide Them

How were participants who continue living in the community willing to entrust themselves to people and to let people’s opinions guide them in making actions?

Nakai (2011) described the importance of understanding mental health and the abilities involved in maintaining mental health [20]. These abilities include the “ability to not be stubborn” and the “ability to resist the feeling of I have to” that allows you to forgive yourself by saying “Well, that is okay,” rather than always seeking perfection. Nakai also stated that when the state of mental health is generally good and smooth, the distinction between ego and the outside world—self and people—is not an issue, and you feel secure.

The study participants may have felt that it was acceptable to entrust themselves to people, rather than feeling that they had to do everything on their own; they may have built this trust through interactions with people who cared about them, who were close to them, who they could rely on, and who they could trust to manage their daily lives and take care of them. This may have led to a change in the participants’ thoughts, developing their willingness to entrust themselves to people and let people’s opinions guide them as an easy way to harmonize with their surroundings.

8.3. Coming to Terms with Negative Feelings about Antipsychotic Drugs

Why do participants who continue living in the community continue taking their medication despite their initial negative feelings about antipsychotic drugs?

Watanabe *et al.* (2014) stated that in the process of transforming the self-concept of people with mental disabilities, “examining their problems among members who are trying to understand them makes it easier for them to face their own issues and leads to a subsequent transformation of their self-concept” [21].

Although participants may initially have negative feelings about antipsychotic drugs, they may be willing to take them to continue their community life in the presence of people who care about them, are concerned for them, and accept them.

It may be easy for participants to accept the abovementioned passionate recommendation for medications or ways to take medications such that they do not feel overwhelmed from people in whom they have placed their trust.

Tai *et al.* (2014) studied the usefulness of utilizing the concept of self-management in nursing assistance and research with patients with schizophrenia. They defined self-management for patients with schizophrenia as “a process in which the patient engages in a decision-making process to address issues that arise in daily life, not limited to disease management, to live better despite the chronic symptoms and disabilities caused by the disease” [22].

We believe that the participants in this study who continue living in the community have come to terms with their negative feelings about antipsychotic drugs; they have accomplished this by deciding to entrust themselves to people or by letting people’s opinions guide them, subsequently deciding to take antipsychotic drugs to maintain their current daily lives.

8.4. Implications for Nursing Care from This Study’s Results

1) Attitude of supporters as patients with schizophrenia continue living in the community.

Shiomi (2016) indicated the importance of caring attitude for people with mental disorders, suggesting the importance of “understanding the pathological characteristics of mental disorders and accepting their pain” and “an attitude that respects the independence of people with mental disorders” [23]. Ohtake *et al.* (2006) stated, “When supporters respect the strengths and wills of patients, the patients are able to adopt their own wishes and intentions and set the pace of life that they desire” [24].

The participants spoke of people they interact with as they continue living in the community as “concerned about me,” “caring and looking after me,” “close and comfortable with me,” “trustworthy,” and “accepting me just as I am.”

Therefore, regarding the attitude of supporters as the patients continue living in the community, we believe that it is important to accept the current situation of the patients with schizophrenia, to lend encouragement to—and be compassionate for—the patients, and to be on the side of the patients.

2) Involvement with patients as they continue to live in the community.

Why did participants who continue living in the community talk about how passionately they were encouraged to take their medications and how they were encouraged to take their medications to ensure that they take their medications without feeling overwhelmed?

Kayama (2017) described the power of words in psychiatric nursing practice and stated that nurses are the ones who can work with (and ask questions) patients to elicit responses [25]. Kayama also stated that “People entrust themselves

to those who trust their words, listen to them carefully, and do not laugh at them. Patients recognize those people as someone to whom they can entrust themselves.” Kayama indicated the importance of drawing out words carefully, taking them down carefully, and asking questions [25].

We believe that the participants could understand the feelings of people who were seriously concerned about them, along with the words that passionately recommended them to take medications. We believe that the patients may have felt encouraged to take their medications in a way that they did not feel forced to do so, and that their wishes were valued rather than the medications being imposed upon them.

Based on this, when considering patients with schizophrenia as they continue living in the community, we believe that it is important for supporters to be a person to whom the patients can safely disclose their feelings as they continue living in the community, and to support the patients’ decisions while asking them questions in words that lend serious consideration to their decision-making.

In the future, we would like to increase the number of subjects and improve the validity of the study.

9. Conclusions

This study investigated what it means for patients with schizophrenia living in the community to continue taking medication. Based on the analysis of the narratives of each of the five participants, the essential structure was read from the perspective of a third party regarding participants’ medication adherence.

A generalized reading of the structure common to the above five essential structures reveals a structure that includes the following three opportunities: 1) Patients realize the importance of people; 2) They sometimes entrust themselves to people or follow people’s opinions when taking actions; 3) They have come to terms with their initial negative feelings about antipsychotic drugs, subsequently continuing to take antipsychotic drugs.

This suggests that the following are important attitudes of supporters of patients with schizophrenia who continue to live in the community: To accept what is happening to the patients, to talk to them with encouragement and compassion, and to be there for them. The study also suggests that it is important for supporters to make patients feel comfortable in opening up while the patients reside in the community, and to support patients in making decisions by showing that they take the patients’ decisions seriously.

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Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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