

Patients' experiences of long-acting injectable antipsychotics: a qualitative study

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Background: In this study, we applied a qualitative approach to explore patients' subjective experiences of long-acting injectable antipsychotics (LAIs).

Methods: Patients undergoing psychiatric treatment from the chronic ward or outpatient department of a medical center in northern Taiwan who had experience with LAI treatment were enrolled. Information was obtained through semi-structured in-depth interviews. The interviews were audio-recorded and then translated verbatim, and the data were collected and analyzed concurrently to develop major themes and categories.

Result: In total, 14 participants (8 female) were interviewed. In a bio-psycho-social model, the participants used LAIs as a method to become "normal," in order to achieve a balance between the "effects" and "side effects" that may influence their daily lives. Their past experiences constructed their concepts about and expectations regarding LAIs, and their relationships with their family members and co-workers also modeled their experiences.

Conclusion: In our study, we sought to understand the experience of LAI in the daily life context of the patients. We attempted to use a bio-psycho-social model to evaluate the subjective experience of the patients; an improved understanding can help mental health specialists gain a closer insight into patient experience.

Keywords: antipsychotics, experience, long-acting injectable, LAI, qualitative research

Introduction

Long-acting injectable antipsychotics (LAIs) have been widely used in the modern treatment of various psychiatric disorders such as schizophrenia and bipolar disorder. The Taiwanese National Health Insurance (NHI) system, with its nearly full coverage, can cover most medical expenditure including LAIs.¹ In 2017, 302,649 doses of LAI were prescribed, with 37.5% were second generation LAIs.² Numerous studies have demonstrated that LAIs can reduce relapse rates and duration of hospitalization;^{3,4} improve medication adherence;⁵ reduce healthcare costs;^{6,7} and improve negative symptoms, suicidal ideation, and personal recovery.⁸ LAIs also ameliorate the severity of disease in aspects of personal and social performance, functioning, and health status.⁹ The medical cost of LAI therapy is also lower than that of oral antipsychotics.¹⁰ Although there are different opinions on whether LAIs confer the aforementioned benefits over oral medicines,^{11–13} growing evidence suggests that LAI usage in early episodes of schizophrenia reduces the risk of relapse and long-term disability associated with the chronic course of the illness.^{14,15}

Although LAIs have become a common therapeutic choice in recent years, most current studies have focused on the effects and tolerability of LAIs. Some previous studies have described the prescribers' preferences,¹⁶ attitudes,¹⁷ and concerns¹⁸

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regarding LAIs. Most studies have used quantitative instruments, and to the best of our knowledge, no qualitative studies from non-Western countries have been conducted. Moreover, with the development of new LAIs with a monthly or even 3-monthly injection period and few side effects, the experience may differ from that with first-generation LAIs. Thus, through this study, we aimed to explore the subjective experience of patients with LAIs in a qualitative manner.

Methods

Design

A qualitative descriptive approach was used in our study to explore patients' subjective experiences of using LAIs. The qualitative methodology uses naturalistic inquiry to yield thick descriptions and explore the experiences of the participants in their own language.¹⁹

We used purposive sampling to select potentially information-rich participants from a medical center in northern Taiwan. Patients with different ages, sexes, educational backgrounds, durations of LAI treatment, and attitudes toward LAIs were selected to maximize the diversity of their experience. Patients were included in our study if they were (1) older than 18 years and with clear consciousness, (2) had received at least one dose of LAI, and (3) been followed up at our outpatient department or admitted in our chronic ward (host psychiatric patients more than 30 days). We did not include patients from acute wards because of their unstable condition, and excluded patients who failed to complete the 40 min interview irrespective of their physical or mental condition. Patients who met the criteria were invited to participate in our study by their attending psychiatrists.

Ethical considerations

This study was approved by the institutional review board of Chang Gung Memorial Hospital. The study procedures were explained to eligible patients; they were informed of their right to withdraw from the study at any time for any reason, and of their right to treatment whether or not they decided to participate in this study. The interviewers (CHL and LLC) had no direct patient-physician relationship with any of the participants. Patients signed informed consent before participation. To maintain anonymity, all recognizable personal data of the patients were protected by replacing their names with code numbers.

Data collection

The interviews were conducted by the two authors (CHL and LLC), using a semi-structured interview guide (Table 1) with open-ended questions to obtain detailed information from the patients. The interviews were conducted from August 1st, 2017 to May 31st, 2018. The average duration of an interview was 41 mins; all interviews were conducted in Mandarin and were recorded. The interviewers recognized their personal views and bracketed them to minimize subjective bias. Demographic data were obtained from the participants and collected through a chart review.

Data analysis

Interviews and data analysis were concurrently performed. We used the phenomenological approach to understand how the participants perceived the world.¹⁹ The recorded interview was transcribed verbatim by the first author (LLC), and coded line-by-line to represent participants' perceptions and experiences by the co-first authors (LLC and CHL). Categories were developed from relative codes, and they comprised the major themes in our study.²⁰ The coding process was performed independently, and then discussed and refined by the co-first authors (LLC and CHL). The consensus was reached under the supervision of a senior medical anthropologist (SCL) who was experienced in qualitative methodology. Two attending psychiatrists (CLC and HLL) confirmed that all themes matched their clinical observations. New participants were enrolled in our study until no further new codes were generated from the interviews (data saturation).

Table 1 Semi-structured interview guide

Questions
1. Please talk about your experience of using psychiatric drugs.
2. How do you benefit from antipsychotics?
3. Did your doctor mention about the reason behind using antipsychotics? What do you think?
4. Why did you decide to use LAI?
5. Have you ever received oral antipsychotics before? What is the difference between them and LAIs?
6. What is the change in your life after using LAIs?
7. Is there any difference between your expectations before and after using LAIs? If so, what is it?
8. What is the attitude of your family and people surrounding you toward LAI? Does that influence you?
9. When I mention about oral pills and/or LAI, what thoughts come in your mind?

Abbreviation: LAI, long-acting injectable antipsychotic.

Results

Eighteen patients who met the inclusion criteria were invited to participate in our study, and three of them refused participation (owing to lack of time). One participant was excluded during the interview because of his psychotic symptoms, and, finally, 14 participants (8 female) completed the interview (Figure 1). Their demographic data are shown in Table 2.

Patient experience of using LAIs can be classified into four major themes: (1) Biological aspect: harmony between the benefits and side effects of LAIs, (2) Psychological aspect: the experience with LAIs is a combination of past experiences and empowerment after injection, (3) Social aspect: the experience with LAIs is related to the relationship with family and co-workers, and (4) The road to “normal”: LAIs as means to recovery (Figure 2).

Biological: harmony between benefit and side effect of LAIs

Most participants reported improvement of psychiatric symptoms after using LAIs. Participant M06 said,

“My auditory hallucinations are gone; if I stop taking these drugs, forget to take medicines or do not have an injection, there will be voices and persecutory delusion, and I will hear the voices taking about me.”

Participant F11 also shared her experience of using LAIs. “I feel that there is improvement of my auditory hallucinations ... The voice seems to have gone away after injection; it is not talking to me all the time.”

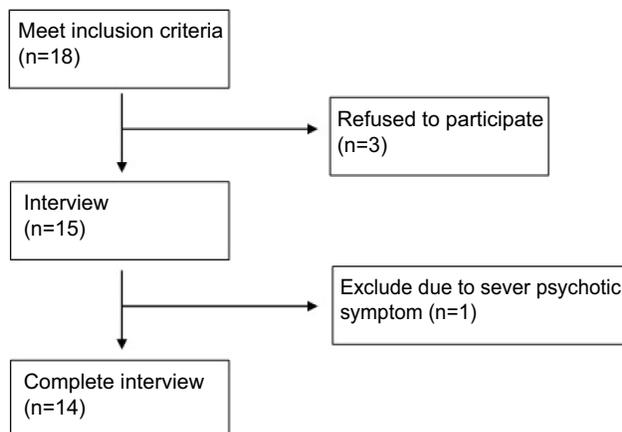


Figure 1 Enrollment of participants.

Moreover, most participants felt that LAIs act faster than oral formulations. Participant F10 said, “Because I think the effect of the injection is faster than taking oral formulations ... it takes about half an hour for the oral tablets, but the injection may be effective immediately.”

Many patients mentioned injection-related pain, which could affect their perspectives regarding the injection. Participant M02 mentioned “hurts a lot!” Participant M05 echoed his experience.

“The only thing I have complained to my doctor is that the nurses who do the injections have different skill levels; some of them are skillful ... but sometimes my wound was big, swollen, and even bled ...”

In addition to the pain, patients said that they felt drowsy after injections, and that such sleepiness affected their normal lives. Participant M01 complained that his daily life was ruined by the sleepiness.

“The time I spend on sleeping at home has increased a lot, nearly 18 hours. I just got up for the toilet and ate one or two meals a day, not eating three meals a day as normal. The effect of LAI is very long, and it influences a lot. (What do you mean by the influence?) It affects normal life, social life, and homework ... that is, I may have to stay at home to rest, could not go to class normally.”

However, whether the sleepiness would be considered as “adverse effect” or “benefit” depended on the daily life scenarios of the patients. Some people admired the sedative effect; for example, participant F08 said that the effect of sleepiness could help her regain energy to continue her work. “Sleeping is okay, because I could regain energy. I have two jobs now, and sleeping is important for me. Insomnia would be a problem and I still need to sleep for my work.”

Psychological: the experience of LAIs is a combination of past experiences and empowerment after injection

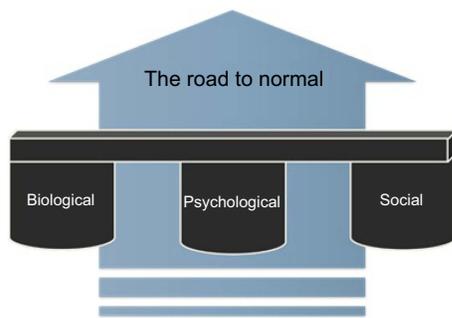
In addition to the biological aspects, participants’ impressions of oral formulations and injections were derived from their life experiences. For example, participant M06 linked injections with the use of narcotics. “Because I had injected narcotics before, felt drowsy ... and receiving long-acting injectables is so much alike.” Participant M03 echoed this experience.

“You have to depend on the drug, not your own will, pretty much like narcotics, keep receiving injections,

Table 2 Demographic data of the participants

No	Sex	Age	Education	Job	Diagnosis	Site	Duration of LAI	Attitude
1	M	44	University	Yes	BD	Ward	Once	Positive
2	M	46	Junior high	No	SCZ, SUD	Ward	2 years	Positive
3	M	NA	Junior high	No	SCZ	NA	6 months	Negative
4	F	29	Senior high	No	BD	OPD	5 years	Negative
5	M	43	University	Yes	BD	OPD	2 years	Neutral
6	M	39	Junior high	Yes	SCZ	OPD	1 year	Positive
7	F	27	Senior high	Yes	BD	OPD	10 months	Positive
8	F	49	College	Yes	SA	OPD	3 year 8 months	Positive
9	F	33	College	Yes	BD	OPD	3 years	Neutral
10	F	49	Senior high	No	BD	OPD	2 year 5 months	Positive
11	F	43	Junior high	No	SCZ	Ward	8 years	Positive
12	F	42	College	Yes	SCZ	OPD	7 years	Negative
13	F	46	Junior high	No	SCZ	Ward	4 years	Positive
14	F	52	Senior high	Yes	SCZ	OPD	5 months	Positive

Abbreviations: BD, bipolar I disorder; OPD, out-patient department; SA, schizoaffective disorder; SCZ, schizophrenia; SUD, substance use disorder; NA, Participant refused to be disclosed.

**Figure 2** Themes to describe participants' experience of using LAIs.

without your own will and power. They are both injections and alike, the only difference is that antipsychotics are good and narcotics are bad.”

According to traditional Taiwanese beliefs, long-term use of Western medicine is harmful to the body. Compared with daily pills, participants considered receiving LAI injections every few weeks to be less harmful.

Participant M02 expressed his fear, “[My family] thought receiving LAIs can be lower than the dosage of pills, which would be much more harmful to my body.” Similar to his viewpoint, participant F07 shared her mother’s consideration. “My Mom preferred injections over pills, and she recommended me to receive injections, because she thought taking pills is too harmful to my body and injections are safer for the same effect.”

With regard to the improvement of psychotic symptoms, patients felt empowered and able to master their lives again. Participant M06 linked LAIs with

independence and a feeling of safety. “Injections are important, it’s a feeling of safety, like you could control everything, and become independent.” Participant F14 shared a similar feeling in her family and at workplace. “[After injection], at least you wouldn’t become others’ burden, you could gain more self-control. (Like who?) Mother, my family, or my boss.”

Some participants said this that feeling reminded them of their life before their disease. Participant F07 mentioned that LAIs gave her a feeling of returning to her daily life before her illness, and she referred to it as going from “abnormal” to “normal.”

“[LAIs] let me to feel like going back to the original me, like the one before illness, and I could learn new things. I will consider LAIs if they can make me go back to my life before illness, with normal daily life, and feel I’m normal. By the time I was sick, I saw myself as abnormal and felt sad.”

Social: the experience of LAIs was related to the relationships with family and co-workers

Some participants mentioned that they had better relationships with their families after their symptoms improved. The relationships with their family members modeled their experiences with LAIs. Participant M02 expressed his definition of being “good” after LAI treatment. “I want to have a ‘good’ life. The ‘good’ means having an ordinary daily life with my family and no arguments ...

Obedience to my family is what I called ‘good.’” Participant F12 also mentioned that not letting her family worry about her is important to her. “Let them less worry about me ... Not letting them feel like I am a loose cannon.”

Some participants returned to their workplaces after the acute stage, but they still required antipsychotics to maintain their functions. They thought that LAIs can minimize the effect of mental illness and assist them to regain their ability in their workplace. Participant M02 said, “Sometimes I need the injection at work to assist me, for example it would make my mind become clear, without deviant behaviors, and not let my boss to feel bad about me.” Participant F14 also stated that LAIs help her concentrate better at work. “Because I worked in a team, and I need to do other tasks so I need to concentrate, otherwise I would make mistakes ... So concentration is important for me.”

The effects and side effects of the medications positively or negatively influenced the workplaces of the participants. Participant M06 hoped that LAIs could totally replace oral pills because taking pills at his workplace intensely bothered him. “I don’t know how to explain if others ask me about what pills I take at my workplace. I am afraid to tell them I have mental illness.” However, frequent hospital visits for injections may be problematic for some patients. Participant F09 preferred oral pills because then she would not require a leave for receiving an injection every month. “Because asking for a leave is difficult for me ... Of course taking oral pills (is more convenient).”

The road to “normal”: LAIs as means to recovery

After the acute stages of their illnesses, the participants noticed that they behaved differently from other people, and from themselves before the disease. Participants constructed their own illness-related experiences, and medication became one of the means to “return to normal.” Participants mentioned the term “normal” frequently during the interview; although their definitions of “normal” differed, most of them viewed themselves as “abnormal” and thought that they required medication (oral pills or injections) to become “normal.” Participant F10 said,

“I need drugs and injections to help me if I’m abnormal. Injections stabilize my moods and make me like a normal

person. Without injections, oral pills may not have enough effect and I would become insane.”

Participants M02 echoed this experience.

“We become ‘good people’ after injections, and other people won’t think we have such illness and see us just like normal people ... No one like to be seen as ‘abnormal.’ We all like to live normally, just to live an ordinary life.”

Some participants experienced frequent relapses. Participant F09 viewed herself as “horrible” in manic episodes. “I don’t want mania to happen again ... becoming a terrible person.” Receiving LAIs became an important way to prevent further relapses for the patients. “I don’t want to relapse anymore, relapsing is terrible ... I don’t want to become that kind of person like before,” said participant M06.

Participants F08 summarized her experiences of receiving LAI.

“Because every time after injection, I felt more comfortable. Though feeling sleepy and I need to sleep at home, but the feeling is very good ... I feel more dignified, and will not be looked down upon by others because of the disability. I used to, because of my illness ... I felt bad because my husband laughed at me and say I am sick. But after LAI injection, it made me feel better ... Yes, I am happy because I feel that I am a useful person.” She also mentioned about her fear of relapse. “I’m afraid of relapse if I don’t receive the injection ... I feel relieved after injection and make sure it won’t relapse. If my symptoms are stable, I can maintain my job, do housework, and keep a good relationship with my family without disturbing them.”

In conclusion, LAIs ameliorated psychiatric symptoms and empowered the participants, and improved their function and relationship with others; thus, they felt empowered and “normal.” The experience of using LAIs became a part of their illness experience, and a part of their daily lives. Participant F08 summarized her experience of LAIs.

“I would like to get injections, even though it may be lifelong. I don’t know. Anyway, taking injections all the time is necessary for my illness. This is my way of living. I’m not affected much by the side effects, so I think receiving injection is better for me and makes me clearer.”

Discussion

Most current studies have focused on the effects of LAIs and the attitudes of the healthcare providers; however, only few studies have focused on the subjective experiences of the patients involved. To the best of our knowledge, this is the first qualitative study to explore patients' experiences of using LAIs in a non-Western country. We found that the experience of using LAIs is a mixture of biological, psychological, and social aspects, and of their interactions with each other. Also, some participants considered using LAIs as a method to become "normal."

In our study, only one participant (F08) mentioned a sense of coercion during the interview; most of the participants did not focus on the coerciveness of the LAIs. This finding differs from that of another study conducted in the UK, which showed higher scores of LAI users than those of oral antipsychotic users, in coercion and negative pressure.²¹ Only 12.5% of the participants in that study had no concern about coercion.²¹ Another qualitative study conducted in the UK also demonstrated a similar consideration of coercion.²² That study included patients within 3 years after being diagnosed with a psychotic disorder.²² In addition to cultural differences, in our study, most of the participants had a long duration of illness and history of using LAIs; thus they may have had relatively favorable experiences about how LAIs positively influence their lives. A qualitative study conducted in Canada revealed that with time, some patients may work through their initial anger or feelings of disapproval toward LAIs.²³ With more experience of using LAIs, patients may modify their initial coercive feeling and recognize more benefit from LAIs.

Most of the participants in our study experienced effects of LAIs, such as rapid control of symptoms, and side effects, such as pain or drowsiness. However, how patients define "effect" or "side effect" depends on the influence of these effects on their daily life. In a previous qualitative study published in 2003, Svedberg et al revealed that LAI injections can elevate the self-esteem of patients, and that it was perceived as a "necessary evil" to balance between movement-related side effects and to avoid suffering from psychotic symptoms.²⁴ The manner in which patients feel the effects may also be influenced by their past experiences of injections. For example, many participants thought the effect of LAI as "rapid onset" compared to that of an oral tablet, which is different

from current pharmacological evidence.²⁵ This difference may arise from their past experience of the "rapid onset" effect of injection; however, this aspect warrants further investigation.

After control of their symptoms, many participants reported a sense of empowerment after taking LAIs. Current evidence showed that LAIs can reduce rehospitalization more effectively than most oral antipsychotics, except clozapine.²⁶ In participants who feared symptom relapse, LAIs improved their confidence of controlling of their diseases and gaining mastery of their own lives. Iyer et al demonstrated that in the focus group, some participants appreciated greater control of illness by using LAIs.²³ Pedley et al also revealed similar result of the "sense of control" being a perceived advantage.²⁷ It demonstrated that better symptom control is one of the important factors that affect the experience of patients, and can even increase their self-esteem.

Oral tablets and LAIs are perceived differently, which can be linked with the past experiences of patients. Some of our participants linked LAIs with narcotics, because both LAIs and narcotics are injected. Linking LAIs with street drugs was also mentioned in a previous qualitative study conducted in the UK.²² Another stigma is also linked with oral tablets, as in Taiwanese culture, consuming too many Western medicinal tablets is considered harmful; thus, injections are preferred over oral formulations owing to lower burdens. Injections can be viewed as convenient or inconvenient, depending on the lifestyles of the patients. Some patients appreciated the monthly administration without the need to take tablets a few times a day; however, some patients thought that an injection is inconvenient because its administration requires hospital visits. A previous qualitative study published in 2013 also revealed a similar result, and the most commonly perceived disadvantage of LAIs was inconvenience owing to the requirement of injections every two weeks.²³ With the development of new LAIs that can be administered monthly or even every three months, the burden of inconvenience may be reduced.

In our study, the relationships of the participants with their family members and their performance levels at their workplaces were important indicators to construct their experiences of medication. Svedberg et al described a similar finding of the importance of maintaining good relationships with others, such as family or friends, among patients in a community mental

health setting who had serious long-term mental illness.²⁴ In the context of their findings, our study demonstrated that patients constructed their experiences of illness and the effects of LAIs from their workplace experiences.

Limitations

Our study has some limitations. First, although there was no direct treatment-related relationship between the interviewer and the participants, a possible bias may exist. Participants may emphasize or hide part of their experience in front of an interviewer “wearing a white coat.” We had attempted to minimize this bias by clearly introducing the interviewer to the participant before initiating the interview, and emphasizing about confidentiality. Meanwhile, interview by a medical staff may encourage patients to be frank and urge them not be afraid of social stigma regarding their narratives about mental illness.

Second, this study enrolled only patients from the outpatient department or chronic ward of one medical center. Patients with poor insight or poor medical adherence were not enrolled in our study; thus, we may have failed to explore their experiences or may have missed some noteworthy negative experiences of medication. Third, the inclusion criteria may have led to the ignorance of patients with notable negative symptoms, such as avolition or alogia. Fourth, this was a qualitative study with a relatively small sample size, and all participants were from a single facility. For more generalized findings of a target population, further studies with larger sample sizes and studies using quantitative methodology may be necessary.

Conclusion

In our study, we sought to understand the experience of using LAIs based on the daily life context of the participants. We attempted to use a bio-psycho-social model to understand the subjective experiences of the patients, and to explore how they use LAIs to become “normal.” More understanding about patients’ experience with LAIs can help mental health specialists discuss patients’ daily lives in detail, and may facilitate the shared decision-making process for using LAIs.

Ethics approval and consent to participate

This study was approved by the Institutional Review Board of Chang Gung Memorial Hospital. The study procedures were well explained to all the participants based

on the guidelines regulated in the Declaration of Helsinki before the written informed consent was obtained.

Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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Author contributions

LLC and CHL designed and conducted the study. LLC, CHL, CLC, HLL and SCL analyzed the data. LLC and CHL drafted the manuscript. All authors contributed to data analysis, drafting or revising the article, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

Disclosure

CHL is a speaker of Janssen and Otsuka. The authors report no other conflicts of interest in this work.

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