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Making Sense of Recovery From First Psychosis With Antipsychotic Medication: A Qualitative Phenomenological Study

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***Background and Hypothesis*: Recovering from a first psychosis is a highly individual process and requires the person to make sense of their experiences. Clinicians, in turn, need to comprehend these first-person perspectives, creating a mutual sense-making dynamic. Antipsychotic medication is a substantial part of psychosis treatment. Providing insight in the lived experience of recovery with antipsychotics could improve the mutual understanding and help bridge the gap between the perspective of the clinician and that of the person recovering from psychosis. *Study Design*: 14 persons in recovery from a first psychosis with the use of antipsychotics were interviewed. Their narratives were analyzed using Interpretative Phenomenological Analysis (IPA). *Study Results*: Five overarching themes were found, representing important and meaningful experiences in recovering with antipsychotic medication. Theme 1: *antipsychotics as external dampening* (4 subthemes); Theme 2: *shifting of realities*; Theme 3: *pace of recovery*; Theme 4: *antipsychotics' influence on identity*; and Theme 5: *is it truly the antipsychotics? Conclusions*: Our findings show that recovery from psychosis with antipsychotics is an all-encompassing, multi-faceted, and ambivalent experience. The themes found in this research could inspire clinicians to discuss less obvious aspects of the experience of recovering with antipsychotics. Even more so, paying attention to the first-person perspective could lead to a more thorough understanding and benefit therapeutic relationships.**

Key words: therapeutic relationship/first-person perspecti ve/identity/stigma/adherence

Introduction

Recovering from a first psychosis is hard to understand for those who have not experienced it. This can create a gap between the person recovering from psychosis and others. Since a collaborative therapeutic relationship is essential to provide care[1] and is valuable for recovery from psychosis,[2] this gap can be problematic.

In the recovery process from a first psychosis, antipsychotic medication often plays a substantial role.[3,4] While clinical recovery has typically been defined as symptom reduction,[5] there has been a shift in the last decades towards recovery-oriented care, which focuses on personal recovery. Personal recovery is described as "a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness."[6] It is a highly individual,[7] active, and unique[8] process, in which connection with the individual sense of self and the social world is a key theme.[9] In psychosis, the recovery journey progresses from the person's pre-psychotic identity and experiences, through understanding and reconciling with the psychotic experiences, to rebuilding a meaningful self and life.[10]

Recovery-oriented care means taking into account people's own ideas about illness and recovery[11] and the complexity of needs,[12] to stimulate finding purpose, meaning, and possibilities in life,[13] and being a member of the community,[13,14] and to help alleviate stigma.[12] The

individual and subjective nature of feeling recovered[15] can make it difficult to fully understand people recovering from psychosis. It requires accurate listening and empathetic understanding while suspending one's own presumptions. Still, a substantial gap can subsist between clinicians and recovering people, due to differences in understanding psychotic experiences, difficulties individuals have in reporting on their experiences,[16] and the mere fact that experiences are always one's own and not directly transmissible. How to bridge this gap between the perspective of the clinician and that of the person recovering from psychosis?

Persons experiencing mental illness navigate their experiences, giving meaning to matters such as illness and recovery, including interactions with clinicians.[17] This often also entails having to make sense of recovering with antipsychotics in the context of psychiatric care. In turn, clinicians strive to understand the persons' experiences, ideally leading to a process of *mutual sense-making* between clinicians and people dealing with psychosis. In this process, acquiring a thorough understanding by the clinician of the complex and personal journey of recovery could benefit the therapeutic relationship.[18,19] Good therapeutic alliance, subsequently, is linked to increased medication adherence,[20–22] engagement in psychological therapy,[23] hopefulness, improved quality of life and willingness to ask for help, and general recovery.[24,25]

Qualitative research can help clinicians in understanding the experience of people dealing with psychosis and antipsychotic medication. A qualitative meta-analysis[26] shows that the perception of antipsychotics evolves, as persons progress from the acute phase to a more recovery-oriented phase, transition from surrender to autonomy, and from being novices to becoming experienced. The authors emphasize the importance of informing persons dealing with psychosis about antipsychotic treatment and being sensitive to changes in their needs.

Keeping in mind the mutuality of the process of sense-making, we would like to add that it is equally important to inform clinicians about peoples' experiences with recovery from psychosis. Since recovery is highly personal, we believe it is important to pay attention to the personal narrative of the person with lived experience, as emphasized in phenomenology. A phenomenological approach is especially crucial when engaging with people experiencing psychosis, exactly because of their fundamentally changed experiences.[16] In the current study, it is our aim to try to bridge the gap between the clinician's perspective on recovery and that of the person recovering from psychosis with antipsychotic medication. Therefore, this study aims to add to the literature on people's experiences with recovery of psychosis with antipsychotic treatment using a qualitative and phenomenological approach. Our research question is: *How do people with first-episode psychosis make sense of recovering with antipsychotic medication?*

Methods

Participants

Persons receiving treatment from the Early Psychosis department in Amsterdam UMC, Amsterdam, or the Early Intervention Psychosis teams of Arkin, Amsterdam, and Dimence, Deventer, the Netherlands, were asked by their clinician to participate. Inclusion criteria encompassed individuals aged 18–60, with a first-episode psychosis within the past 3 years; using antipsychotic drugs for at least 2 months, and able to provide informed consent. Exclusion criteria were acute severe psychotic symptoms posing a risk of functional decline or harm. With these selection criteria, we intended to include a group of participants who could vividly report on their first psychosis and recovery during their first treatment with the use of antipsychotic medication.

Recruitment proceeded until data saturation was reached, defined as the point where additional interviews no longer yielded new information.[27,28] Rather than setting a predetermined sample size, recruitment was dependent upon the richness of descriptive data obtained from each interview.[29] During the presentations of the individual findings to the research group, the saturation of the data was discussed. When we did not encounter new themes in several subsequent interviews, we decided to stop the data collection.

The final sample comprised 14 adults with a DSM-5 classification of a schizophrenia spectrum disorder who had experience with antipsychotic medication: 4 females, and 10 males with ages ranging from 22 to 56 (table 1), pseudonyms are used.

Procedures

All participants received comprehensive information, both verbally and in writing, detailing the study's objectives, methodology, potential benefits and drawbacks, and data storage procedures. Informed consent was obtained through participants' signatures. It was emphasized that withdrawal from the study was possible at any stage. One interviewer (SB, psychiatrist/MD, PhD) maintained a therapeutic relationship with 3 participants, introducing a potential conflict of interest. To mitigate this risk, the researcher clearly conveyed to participants that their study involvement would not impact their treatment.

The study received an exemption from a full review by the Medical Ethics Committee (METC) of the Amsterdam University Medical Center, location Academic Medical Center (Reference number W22_147 # 22.192). The reason for this was that the project was not subject to the Dutch Medical Research Involving Human Subjects Act (Wet Medisch Onderzoek, WMO), as participants in this study were not subject to procedures or interventions, or required to follow rules of behavior.

Table 1. Individual Participant Characteristics

Pseudonym	Gender	Age	DSM-5 classification	Antipsychotics	
				Current	History
Joan	Female	55	Other schizophrenia spectrum and other psychotic disorder	Aripiprazole	Aripiprazole
Alissa	Female	56	Other schizophrenia spectrum and other psychotic disorder	None	Haloperidol
Sebastian	Male	28	Schizophrenia	Amisulpride	Quetiapine
Damian	Male	28	Schizophrenia	Olanzapine	Olanzapine
Matthew	Male	30	Schizophrenia	Paliperidone	Haloperidol, Aripiprazole, Olanzapine, Risperidone, Penfluridol
Bill	Male	27	Other schizophrenia spectrum and other psychotic disorder	Quetiapine	Risperidone, Quetiapine
Nicholas	Male	24	Schizoaffective disorder	None	Haloperidol
Mike	Male	26	Schizoaffective disorder	Olanzapine	Quetiapine, Olanzapine
Melanie	Female	28	Schizoaffective disorder	Aripiprazole	Olanzapine, Quetiapine, Aripiprazole
Andrew	Male	26	Schizophrenia	Amisulpride	Haloperidol, Amisulpride
Dylan	Male	27	Schizoaffective disorder	Amisulpride	Amisulpride
Katie	Female	24	Brief psychotic disorder	Olanzapine	Olanzapine
Samir	Male	22	Schizophrenia	Amisulpride	Haloperidol, Amisulpride
Cole	Male	26	Schizophrenia	Amisulpride	Aripiprazole, Amisulpride

Interview protocol

A phenomenological interview protocol was formulated in accordance with recommendations for phenomenological interviewing in general[29] and for psychosis specifically.[16] In order to explore the sense-making process of people recovering from psychosis with antipsychotics, it was our aim to capture participants' first-person perspectives as best as possible and to allow for all possible experiences to be reported upon. Therefore, we strived for as minimal preselection on topics as possible. Instead of any specific questions about recovery or antipsychotic medication, we solely asked about their experiences during recovery from psychosis. The interview started with an open-ended question, asking participants to share their experiences with current, or past psychotic episodes. Subsequently, participants were asked to elaborate on their (alterations in) experiences during and after using antipsychotics. To ensure rich data, open-ended questions were employed, encouraging detailed, and reflective responses with examples. The interviews maintained minimal structure, enabling participants to elaborate on personally significant experiences. Interviewers aimed to remain aware of and set aside their personal preconceived ideas and knowledge (ie, "bracketing"). For data collection, Levitt and colleagues'[30] principles for methodological integrity concerning fidelity (adequate data and perspective management) and utility (contextualization and catalyst for insight) were taken into account. With the selection of the specific participant group, that is, people recovering from psychosis with the use of antipsychotics and the open-ended inquiry of experiences in a minimally structured way, we were able to gather rich data that was contextualized, and insightful for our study goal. The bracketing of own preconceptions by the interviewers during the minimally structured interview contributed to perspective management in data collection.

Data collection

In-depth interviews, in one or two sessions, took place at the aforementioned psychiatric care facilities. Interviews were conducted by researchers, RB (MD), TH (MD), and SB, all trained in phenomenological interviewing. The first 2 interviews were done by SB and were used to pilot test the interview protocol. These interviews were included in the study. After, 2 interviews were done by RB and TH together and the remainder of the interviews were done separately. All interviews were conducted in Dutch, audio-recorded, and transcribed verbatim for subsequent analysis. Analysis was provided to participants on request. Translation of quotes into English was performed during the writing process.

Data analysis

While during the interview minimal structure and direction were used to gather as much information on relevant experiences and the sense-making process, analysis focused on the specific research question: how do people make sense of recovery from first psychosis with antipsychotic medication? Analysis was done with Interpretative Phenomenological Analysis (IPA)[29] as this promotes to explore the first-patient perspective in a structured, yet flexible manner. The bottom-up methodology of IPA

that prioritizes the depth, richness, and complexity of individual narratives made it the most suitable method to analyze the process of making sense of one's experiences in recovering from psychosis with the use of antipsychotics. Implementing the following seven IPA steps, each interview transcript was read twice for familiarity (1). Sections where participants reported on antipsychotic experiences were selected. Next, exploratory notes were made to capture initial impressions and elements of importance to the participant (2). The exploratory notes formed the groundwork for the next interpretative step, constructing experiential statements for each participant (3). Experiential statements contain an interpretative summary of multiple exploratory notes, capturing direct experiences, and participant sense-making of recovery with antipsychotics. Exploring connections and contradictions (4), experiential statements were clustered and named, creating personal experiential themes (PET) (5) for each participant (6). Finally, group experiential themes (GET) were created by identifying common high-order themes across participants, encapsulating the core aspects of the lived experience in this patient group (7). Analysis was done using qualitative research software MAXQDA 22.7.

For analysis, Levitt and colleagues'[30] criteria for fidelity (perspective management and groundedness) and utility (meaning contribution and coherence) in data analysis were taken into account. Applying the hermeneutic circle, a dynamic relationship between parts and the whole[29,31] was maintained throughout the analysis. This meant that rather than a linear progression, the process involved continuous revisiting and reinterpreting data for a thorough and nuanced understanding, while at the same time staying aware of interpretation choices. Analyst triangulation[32] aimed at preventing selective interpretation and developing a thicker understanding of the data, improving credibility, and confirmability.[33] Diversity within the research group, for example, medical and non-medical disciplines, amount of work experience in general and experience in psychosis-related care specifically, and an environment that welcomed open discussion of differences from every member contributed to this process of triangulation.

The research group gathered in different compositions for about 32 h spread across 11 meetings. Initial analysis of the PET of 2 transcripts (Sebastian and Matthew) was collaboratively conducted by 2 researchers (SD, psychologist, and philosopher, and JR, MD). Subsequent individual analysis of one transcript (Nicholas) by JR and SD allowed for comparison and discussion. Analysis of another transcript (Bill) involved the entire research group, (SD, JR; SB, MdK, psychiatrist/MD, PhD, and LdH, psychiatrist/MD, PhD). Finally, JR analyzed the remaining interviews, presenting all results to the research group. The formulation of the GET was a collaborative effort between SD and JR, later reviewed by the research group.

Results

The analysis resulted in 5 common high-order themes representing common and contrasting experiences (table 2). An overview of supporting quotes of all (sub)themes is provided is shown in table 3.

Theme 1: Antipsychotics as external dampening (N = 13)

A majority of participants spontaneously reported about the effect of the antipsychotics. A commonality in their reports was the dampening effects of the medication. However, there were variations in how this was experienced. To grasp these differences, subthemes were created.

Subtheme 1A: Emotional dampening (N = 8)

Antipsychotics were reported to have a suppressing effect on emotions. Participants describe how their feelings went from "very chaotic to just calm" (Sebastian) and how antipsychotics helped them to "experience things a little less intense" (Matthew). This effect of the medication was often reported as pleasant and sometimes also necessary. For example,

> *My feelings were too strong. I can't really describe what kind of feeling it was, but it was too strong. And that flattened a little bit, which was pleasant. Because I couldn't handle it.* (Bill)

Subtheme 1B: Dampening of thoughts (N = 8)

Changes in thoughts and thinking were reported as an effect of the antipsychotics, also providing a glimpse of what thinking was like during psychosis. Some participants reported fewer thoughts or being able to slow down their thinking. Others reported how antipsychotics seemed to help them take some distance from the whirlwind of quick and increased associative thoughts. Participants explained how the medication helped them to not "disappear in their thoughts as deep as before" (Nicholas), to "not get so entangled" in their thoughts (Matthew), and that their thoughts "didn't digress as before" (Bill). Bill also reported how the antipsychotics prevented thoughts "from jumping up on their own."

With this change in thinking, some participants experienced that they regained their personal capacity for thinking well again. They were able to "organize" or "structure" their thinking and regained "their critical view." Damian explains the difference like this:

> *At this moment [with antipsychotics] I do think a lot, but they are deliberations, so to say. I'm making progress, draw my conclusions. Then I have options and I will go for the one option or the other, which I think is best. And at this moment it works reasonably well.*

Some participants experienced the antipsychotics clearly as an external influence, exerting an effect on them. They explain how their thoughts became more "streamlined,"

Table 2. Group Experiential Themes

	Total	Joan	Alissa	Sebastian	Damian	Matthew	Bill	Nicholas	Mike	Melanie	Andrew	Dylan	Katie	Samir	Cole
Theme 1: Antipsychotics as external dampening															
Subtheme 1A: Emotional dampening	8	+	+	+	−	+	+	+	+	−	−	+	−	−	−
Subtheme 1B: Dampening of thoughts	8	−	−	+	+	+	+	+	+	−	−	−	+	−	+
Subtheme 1C: Experiences persist but are less disruptive	7	−	+	+	+	+	+	−	−	−	−	+	−	+	−
Subtheme 1D: The inner flame is extinguished	8	−	+	+	+	−	−	+	+	−	+	+	−	+	−
Theme 2: Shifting of realities	9	+	+	+	+	+	−	−	−	+	+	+	+	−	−
Theme 3: Pace of recovery with antipsychotics	13	+	+	+	+	+	+	−	+	+	+	+	+	+	+
Theme 4: Antipsychotics' impact on identity	5	+	+	−	−	−	−	+	+	−	+	−	−	−	−
Theme 5: Is it truly the antipsychotics?	10	+	−	+	+	+	−	+	+	+	−	+	+	+	−

"restrained," and "kept in line." Matthew articulates it as follows:

> *I was giving meaning to everything again, but I did notice that I got less sucked into it again. That I was able to keep it under control. So yeah, you do notice that it is has some sort of protective effect on you, the medication.*

Subtheme 1C: Psychotic experiences persist, but are less disruptive (N = 7)

Half of the participants reported that some of their psychotic experiences persisted, but that the impact somehow was reduced by the medication.

Several participants explained how they still had the same thoughts, but that these thoughts lost their importance. The thoughts were "less lively," or the participant "cared about them less." Others explained that the medication made them too "drowsy and tired" to engage in thinking, or that they could not keep up with it because of a "lack of concentration."

Other participants reported similar experiences, but related to hearing voices:

> *I still hear voices from within, but I don't suffer from them anymore. Yes, it's less of a burden. I don't make it into such a big problem anymore.* (Samir)

Another participant explains how this extends to the experience of his surroundings:

> *Watch a horror movie and you'll find yourself in a certain atmosphere. That feeling, constantly. I believe the antipsychotics helped reduce that. […] I think I could handle it better because of that, that it was all dampened.* (Bill)

Subtheme 1D: The inner flame is extinguished (N = 8)

The dampening effect of the antipsychotics is not solely perceived as pleasant. Even though participants report the positive effects on their symptoms, there is a flipside. Several participants reported a loss of energy, feeling drowsy, and sedated in day-to-day life. The loss of uncomfortable symptoms entailed the loss of pleasant ones too: the fire is put out, but now the inner flame has also been extinguished. Sebastian explains it like this:

> *And the next day, I noticed that I kind of completely… collapsed on one hand. So, all that energy and strength within me just drained away or something. And I became very tired. I felt a kind of total exhaustion washing over me, so to speak. And of course, that was not really a pleasant feeling, but on the other hand I did have the feeling all the negativity dissipated.*

Table 3. Quotes Supporting Themes and Subthemes

Theme 1: Antipsychotics as external dampening ($N = 13$)

Subtheme 1A: Emotional dampening ($N = 8$)

- Alissa: *Yes, I mean a dampened world is quite pleasant because then, nothing really hits as hard.*
- Dylan: *At first you feel constant tension. So, you feel tension in your abdomen, arms, chest, back and legs… And when you take medication, you feel the tension less, because you are less anxious.*
- Joan: *At a certain moment, it maybe was pleasant too, that not everything hits so hard, so to speak… I was just able to look at things more lightly.*
- Mike: *It just kept on coming… and in the moment I could panic so much. And that was reduced due to the sleeping medication and the antipsychotics. […] Thoughts did not hit as hard.*
- Nicholas: *Initially when you start to take medication, it gives you a sense of calmness. That is pleasant because, well, you get overwhelmed when everything happens one thing after the other. And at a certain point, you actually need that calmness.*
- Sebastian: *Mostly that the antipsychotics reduced my strong feelings. […] So, my emotions and feelings became less intense.*
- Bill: *My feelings were too strong. I can't really describe what kind of feeling it was, but it was too strong. And that flattened a little bit, which was pleasant. Because I couldn't handle it.*
- Matthew: *So yeah, it did help back then, to experience things a little less intense.*

Subtheme 1B: Dampening of thought ($N = 8$)

- Sebastian: *At this moment [with antipsychotics] I do think a lot, but they are deliberations, so to say. I'm making progress, draw my conclusions. Then I have options and I will go for the one option or the other, which I think is best. And at this moment it works reasonably well.*
- Damian: *I think the medication actually helps to keep it [thoughts] in line, so to say, that you don't immediately flip out.*
- Matthew: *There are still thoughts, but you get not so entangled in them, or something. […] That it gets more streamlined in your head, or something.* And: *It does sometimes have an inhibiting effect. So that you… still have those thoughts, but you get less caught up in them.*
- Bill: *Yes, that I became calmer. That my thoughts didn't digress as before.* And: *It calmed my thoughts a little bit. That they don't jump up from on their own, so to say.*
- Mike: *And I also felt like my thoughts came to rest. And it sometimes took a bit less effort because of those antipsychotics. It became somewhat more naturel. (Less effort for what?) For having fewer thoughts.*
- Cole: *Yes, you feel like you have more control over it [thinking] and you are able to decide what is right and what is not.*
- Katie: *It actually became too much, that those thoughts were racing so quickly. […] I needed more medication to calm my head down. […] Then something changed in the medication that really helped, so that was pleasant.*
- Nicholas: *To briefly pause, not disappear as deeply into your thoughts, distance yourself and calm down.*

Subtheme 1C: Experiences persist but are less disruptive ($N = 7$)

- Alissa: *Uhh, that I had less concentration, I didn't have enough concentration for the computer, […] So, the concentration became less and less, so that I was able to search less.*
- Sebastian: *All those problems… yeah, what does it matter anyway, so to say. While I was still thinking it was the case, but because of those medicines I didn't care about it all.*
- Bill: *Yeah, it flattens everything a little bit. Flattens it. Yeah, maybe also less deep thinking. But they [the thoughts] were there for a long time, even when I was using medication.*
- Dylan: *Look, I need to be honest. In the beginning, when I just had the medication, I told my mum: "yes, those people are still badmouthing me, but I just don't care anymore". […] and I really thought it was the case. But yeah, I didn't care about it anymore, I thought: "let those people be".*
- Samir: *I still hear voices from within, but I don't suffer from them anymore. Yes, it's less of a burden. I don't make it into such a big problem anymore.*
- Damian: *I can believe that the world is a simulation and draw my conclusions, create my own conspiracy theories and act on it. How far will I even get? What even is the point, you know?*
- Matthew: *Those thoughts, they were simply still there but maybe they get less vivid, or something? But they're still there.*

Subtheme 1D: The inner flame is extinguished ($N = 8$)

- Alissa: *Yes, very dampened and very slow, I was there but wasn't at the same time. […] If you do something, you need attention. Attention… Concentration to do something and you don't have it. So really, you don't do much.*
- Andrew: *When taking that medication long-term, I very much suffered from those negative symptoms. So, apathy and less activation.*
- Damian: *I just noticed… Actually, the only thing I noticed was the high dose I had, I believe 20 milligrams and err… because of that I was very drowsy.*
- Dylan: *How I always put it, is that with less medication I get more fire in me. What I mean by that is, more… drive to fight and achieve my goals.*
- Mike: *I just really missed that period that I just felt euphoric. I can remember that I really was in deep grief. I felt it through my whole body, that grief. It really was grief-grief, that I experienced.*
- Nicholas: *There was no connection anymore, I no longer had any pleasure in life, there was absolutely nothing. It was depression, apathy, no energy, no zest for life, no prospects, no… It was just horrible.*
- Samir: *I am a little less energetic. I am a bit more tired so to speak. So that is just because of the medication.*
- Sebastian: *It does make you very, very drowsy and extremely tired and stuff. And, well… you do become somewhat like a persistent vegetative, so to speak.*

Table 3. Continued

Theme 2: Shifting of realities due to antipsychotics (N = 9)

- Joan: *That was the first time I noticed that the medication was doing its job. That I was back in reality again, in the reality where everyone else around me also was in.*
- Alissa: *Because that world, of the psychosis, that is correct, right. You are completely immersed in it. And then you are taken out of it and then that world is not right. (What is not right?) Your world is not right anymore... it didn't feel like your world anymore. (How did that feel?) Well, quite scary.*
- Sebastian: *My perspective on how the world is, is back to how it was before. […] While compared to the moment was psychotic, I had built a totally different perspective of the truth, how people are and what they do… so, I have been letting that go.* And: *I felt very relieved on one hand, but on the other hand I felt displaced, so to speak. You held on to a certain truth for a long period of time and at once, you let it go. And that kind of gives a displaced feeling.*
- Damian: *I have to say, currently, I still hear voices sometimes and then I'm like: err, this is all exactly at the right moment. And then you start to wonder: could there be a general "them" who control everything […]? But I remain skeptical and agnostic, as long as I don't experience a psychosis.*
- Matthew: *It does haunt you, because especially in the beginning when you just started recovering, when says something, certain thoughts can still arise. Like, maybe he means it this way… or it could mean that. So, part of it is still there, you just label it differently, like a psychotic symptom or something that is simply not true.*
- Melanie: *Imagine, I have had 1000 delusions. Now, I have gotten rid of 90 percent, but with every delusion distance yourself from, it is like a loss. Like, this was your reality. And that made severe emotional impact.*
- Andrew: *But yeah, taking medication. In the beginning, I didn't really notice anything. No, I didn't really notice anything, but I did just came, slowly, back to earth. That I had the feeling of "I can see everything in reality again" and, yeah, I'm no longer very confused.*
- Dylan: *At a certain moment you realize: everything I experienced was fake. Now I am back in reality. And then you are very shocked. Because you just threw away a few months of your life, to things you should not have had to do.*
- Katie: *Well, it came as a shock because… I thought I was cured, but I also thought: if I am not cured, then what happened? I had my doubts before, that I was thinking: "I'm having a psychosis, this isn't going right", those kind of things. But when I felt the pain again, then came the shock, like: "okay, maybe I'm not better, but then what has happened?". So that was heavy.*

Theme 3: Pace of recovery with antipsychotics (N = 13)

- Joan: *I felt like it got better very quickly… That I sort of, "plop!", sort of plopped, plopped out of it.* And: *That was gone the whole time and is slowly starting to come back now.*
- Alissa: *I thought it went pretty quickly, that I did not have the focus for it anymore.*
- Sebastian: *It actually lies past me, so more time has passed that it is going well. And that I also had positive experiences from which I can derive that it's getting better.*
- Damian: *I think after one week I could say that my psychotic thoughts minimized.*
- Matthew: *It really went gradually, I noticed. I thought by myself: everything you have thought, it just is not true and the world is just… it is what it is, and not everything means something. And then gradually, I relearned everything.*
- Bill: *I think it went very slowly, especially in the past months, things got better and better.*
- Mike: *Then it faded away. It just slowly passed. And slowly, it just got… better for me.*
- Melanie: *A new state of being that didn't just happen overnight, but over a very long time. […] So yeah, that change is like your nails growing. You don't notice it.* And: *You have to gradually replace what was very emotional at the time, with new experiences in which you are in your right mind, so to speak.*
- Andrew: *I do have the feeling that I'm slowly growing towards my own beliefs and who I am as a person. So yeah, it's a slow process… And that is also about getting a bit of trust, slowly, when you are stable for a longer time.*
- Dylan: *Within one week the voices were already gone. And yeah, within one week I became less psychotic.* And: *And at a certain point you take medication and the voices go away. And then you still think about something occasionally, but it becomes less and less… gradually.*
- Katie: *And my thoughts going too fast, that was under control pretty quickly at one point.* And: *I did have the feeling God was trying to tell me something, but that gradually faded.*
- Samir: *I think that gradually, it all got better.*
- Cole: *(You are talking about social contact, right? Did that change in any way or is it still the same?) No, I think it gradually became better.* And: *Yeah, maybe feeling. (How did that go?) That gradually became more after my psychosis. (And what do you mean by "more"?) Better.*

Theme 4: Antipsychotics' impact on identity (N = 5)

- Joan: *Yes, I am a lot less motivated to do anything. I've actually become a different person, I think. Say my characteristics, which made me Joan, well part of it is gone… […] That can make me sad.* And: So, your feelings and your body don't align with who you really were. […] It's true, it really makes me… it just doesn't align with who you were for years. And: *That it the annoying part, because it can make me emotional, because you're not, you're not like…the person you were before.*
- Alissa: *Usually I am fast, I can handle speed. […] And back then, I could not. Then you start to doubt yourself, like: can I not do it? But then you do not think it is due to the medication yet, but you think it is because of yourself.*
- Nicholas: *Oh yeah, I became a completely different person. (How did that feel?) Terrible, I think that, at one moment it became so bad that, despite all the negative experiences that happened before, I decided to stop the medication. With the risk that the symptoms would return, the medicine was that bad to me.*
- Mike: *My self-image got really bad because of the pills. I thought it was not cool at all to take those pills. I thought: "alright, only suckers take those pills".* And: *[starting antipsychotics] I was put in my place, so to say. I needed to investigate my position in society. Uhm, because where I first thought: "okay, I'm the new Leonardo da Vinci", it now was very different all of a sudden, since I was just a patient at the crisis department in [city]. And since I was taking antipsychotics and was living with my parents again, I thought: "I really need to reevaluate who I am. And that's where I made the start […] of getting a sort of more adequate self-image.*
- Andrew: *And that had distanced me somewhat from who I really am. But I think that now, little by little, I am growing back into myself because I have been stable for a longer period of time.*

Table 3. Continued

Theme 5: Is it truly the antipsychotics? ($N = 10$)
■ Joan: *I was more passive, In the beginning, when I started the medication, but yeah, that can also be because of the psychosis itself, right. […] So, what is because of what?*
■ Sebastian: *Well, it does raise the question how much the antipsychotics contributed, or the treatment from the clinic with all the conversations I had there. Because of course, antipsychotics is part of a full treatment plan.*
■ Damian: *That antipsychotic medication… It does help, but I'm still wondering to what extent, because that is very difficult to determine, even if you take it.* And: *It's really hard to say to what extend the medication has an effect on me. […] I can't go back in time, and not take my medication and see what would've happened then.*
■ Matthew: *I sometimes find it very difficult to pin down, like "ok, what is the cause of this?" Is it the medication? Or is it because I also really engaged in development?* And: *It mainly was my own cognitive functions that got me out of my delusions and out of those convictions. And after coming to terms with everything, reflected on it, then the moment came that I started noticing the effect of the medication. […] Yes, the medication is like the cherry on top of the cake, and the cake I bake myself. And the cherry finishes it, you know?*
■ Nicholas: *Maybe that on the moment someone is able to… Uhh, well, like was the case with me, to be objective towards your own ideas, and not be completely entangled in a psychotic state, that an antipsychotic is not even necessary per se.*
■ Mike: *And that really was an amazing period of time. I actually recovered very well because of that. Because I had people around me, who were also recovering from psychosis and because I just had real starting points there, to learn more about myself and to learn from others. Because of that I actually recovered well.*
■ Melanie: *That I had to go to bed early, get out of bed in the morning in a nice, structured way. And that the nurses were very sweet. That I could talk to them well. The antipsychotics… Yeah, I think the miracle cure was just sleep… And the safe environment.*
■ Dylan: *But you know what's funny, when I was really in a psychosis, like deep into it, I also started watching videos. Because when I was diagnosed, when I heard it, I started to watch videos about what a psychosis is. […] That is what really helped me so that I could say about myself that I had a psychosis. […] And that is why I recovered so quickly.* And: *But I believe that if you perform certain acts, that someone with psychosis eventually also can recover without medication. That is pure exercise. How to deal with certain thoughts. […] It's the same with voices. If, at one moment, you can just set those voices aside, then, yeah, you can get rid of it without medication.*
■ Katie: *I do not know what olanzapine did and what happened by itself, so to speak. So, olanzapine becomes…Well, I do not really know.* And: *With the help of medication it became less intense and the overstimulation dissolved. What helped a lot, indeed, was going out for a walk, do something with your hands, and then lie down in a dark room. I did that for a long time, alternating those things.*
■ Samir: *(What makes that you are feeling better now?) Yeah, I have no clue, honestly. I sometimes ask myself that as well. I think it is the trajectory. Being involved in it… putting focus on the outside world and learning about what psychosis is and such. And I think that automatically provided some sort of tranquility.*

Losing and missing some parts of the psychotic experience can be deeply felt, as Mike says:

> *I just really missed that period that I just felt euphoric. I can remember that I really was in deep grief. I felt it through my whole body, that grief. It really was grief-grief, that I experienced.*

Theme 2: Shifting of realities ($N = 9$)

A substantial part of the participants describe their experiences in terms of "realities," "world views," or "the world of the psychosis." It seems that participants experienced different kinds of realities and that recovering from psychosis means a shift in those realities. Joan describes it as a shared reality:

> *That was the first time I noticed that the medication was doing its job. That I was back in reality again, in the reality where everyone else around me also was in.*

Getting back to reality was not a merely positive experience for everyone. Several participants explained that leaving their psychotic reality caused them to feel "displaced" and "shocked" or that it made "a severe emotional impact." Alissa reports that the non-psychotic reality feels wrong and scary:

> *Because that world, of the psychosis, that is correct, right. You are completely immersed in it. And then you are taken out of it and then that world is not right. (What is not right?) Your world is not right anymore... it didn't feel like your world anymore. (How did that feel?) Well, quite scary.*

Having lived in 2 realities can be confusing. Suddenly, reality becomes relative, and the truth is not self-evident anymore. This can cause doubt about the validity of their experiences, and whether they can trust their own thoughts, as Sebastian illustrates:

> *I still occasionally think back about that period, like, what was actually true of what I thought and what was not true at all? What was reality? What was not? All those things.*

Some participants, like Damian, report to not completely return to the shared reality and they seem to keep on making a distinction between realities:

> *I have to say, currently, I still hear voices sometimes and then I'm like: err, this is all exactly at the right moment. And then you start to wonder: could there be a general "them" who control everything […]? But I remain skeptical and agnostic, as long as I don't experience a psychosis.*

Theme 3: Pace of recovery (N = 13)

All participants, except for one, spontaneously commented on their pace of recovery with antipsychotics. Six of them mentioned a rapid effect on their symptoms, like Joan:

> *I felt like it got better very quickly… That I sort of, "plop!", sort of plopped, plopped out of it.*

However, the majority, including some who initially noticed a rapid effect, talk about long-term, gradual recovery. Participants speak about a "gradual decrease" of symptoms, "gradually getting better," and "regaining a bit of trust after being stable for a long time." Recovery also seems to be a process that is noticed and understood afterward. Melanie describes:

> *A new state of being that didn't just happen overnight, but over a very long time. […] So yeah, that change is like your nails growing. You don't notice it.*

And,

> *You have to gradually replace what was very emotional at the time, with new experiences in which you are in your right mind, so to speak.*

Sebastian adds,

> *It actually lies past me, so more time has passed that it is going well. And that I also had positive experiences from which I can derive that it's getting better.*

Theme 4: Antipsychotics' impact on identity (N = 5)

A few participants mentioned that their sense of identity came into play in recovery from psychosis with medication. This happened in several manners.

For 2 participants, the dampening effects of the medication and the accompanying weight gain conflicted with their sense of identity, making them feel like another person. Joan illustrates,

> *Yes, I am a lot less motivated to do anything. I've actually become a different person, I think. Say my characteristics, which made me Joan, well part of it is gone… […] That can make me sad.*

On the other hand, Andrew identified a positive shift in identity during recovery: from his disrupted psychotic identity to "growing back to his true self." Mike describes a more ambivalent process concerning his identity. He explains how he had to relate to himself,

> *[starting antipsychotics] I was put in my place, so to say. I needed to investigate my position in society. Uhm, because where I first thought: "okay, I'm the new Leonardo da Vinci", it now was very different all of a sudden, since I was just a patient at the crisis department in [city]. And since I was taking antipsychotics and was living with my parents again, I thought: "I really need to reevaluate who I am". And that's where I made the start […] of getting a sort of more adequate self-image.*

In the process of reevaluation, Mike also deals with self-stigma because of taking antipsychotics:

> *My self-image got really bad because of the pills. I thought it was not cool at all to take those pills. I thought: "alright, only suckers take those pills".*

Theme 5: Is it truly the antipsychotics? (N = 10)

A majority of the participants spontaneously reflected on the role of the antipsychotics in their recovery, and experienced difficulty determining their exact influence.

> *That antipsychotic medication… It does help, but I'm still wondering to what extent, because that is very difficult to determine, even if you take it.* (Damian)

And,

> *I sometimes find it very difficult to pin down, like "ok, what is the cause of this?" Is it the medication? Or is it because I also really engaged in development?* (Matthew)

Some participants highlighted that other elements were also important for recovery, like "being surrounded by others also in recovery and learning from them," "the treatment and conversations in the clinic," and "working on yourself and wanting to recover." Melanie mentions a couple of other important elements,

> *That I had to go to bed early, get out of bed in the morning in a nice, structured way. And that the nurses were very sweet. That I could talk to them well. The antipsychotics… Yeah, I think the miracle cure was just sleep… And the safe environment.*

Others reported that, instead of the antipsychotics, they primarily induced their own recovery. Nicolas' opinion is that for recovery, antipsychotics are not necessary per se, "if someone can be—what I had—objective towards your own ideas and not be completely entangled in psychotic state." Matthew also mentioned that his own cognitive functions primarily helped him in recovery,

> *It mainly was my own cognitive functions that got me out of my delusions and out of those convictions. And after coming to terms with everything, reflected on it, then the moment came that I started noticing the effect of the medication. […] Yes, the medication is like the cherry on top of the cake, and the cake I bake myself. And the cherry finishes it, you know?*

Discussion

The main aim of the current study was to bridge the gap between the clinician's perspective and that of the person on recovering from psychosis with antipsychotics. To this aim, we explored how persons experiencing a first

psychotic episode make sense of recovering with antipsychotics using phenomenological interviewing and IPA. Five common overarching themes were identified, representing important and meaningful experiences in recovering with antipsychotic medication.

Theme 1 concerns the experience of the dampening effects of antipsychotics. These findings could be understood as the experiential side of Kapur's aberrant salience hypothesis.[34] The reported experiences headed under the other themes underline that recovery from psychosis with antipsychotics is a complex, all-encompassing, and ambivalent experience, affecting the experience of self and the world. Psychosis has earlier been described as a profound ontological transformation, that is, a change in the experience of reality.[35] Our research shows that recovering from psychosis entails a similar ontological shift. This is not simply a return to the previous state, from before the psychosis. Participants express complexity and ambivalence. They note feelings of grief, displacement, confusion, and shock. Some describe missing aspects of their psychotic experiences despite symptom relief. These ontological shifts are often accompanied by the experience of reality as relative rather than absolute, challenging the perceived certainty, and validity of current and past experiences. Some experience a dual reality, known as double bookkeeping,[35,36] maintaining awareness of both realms and being able to separate them. Furthermore, our research underscores the profound impact on identity that recovery and the use of antipsychotics have. While on the one hand, people start feeling more like themselves again, on the other hand, participants elaborate on losing their personal characteristics and engaging in self-stigma. Finally, many participants refer to the time it takes to fully recover. They particularly emphasize the importance of gaining new, positive, and reassuring experiences to replace psychotic experiences in their process of recovery. While elaborating on the functioning of antipsychotics, many recovering individuals do not attribute recovery solely to antipsychotics.

Earlier qualitative research on recovery from psychosis[9,10] and on antipsychotic treatment[26,37] focused on either one or the other. Although some qualitative research on recovery from psychosis addresses medication,[38–40] and one study focused on the experience of antipsychotic medication in clinically recovered people,[41] the current study is the first, to the best of our knowledge, that explicitly examines both subjects in connection to one another. Furthermore, our research differs from earlier qualitative research due to the phenomenological method used. Our open explorative approach allowed participants to describe their experiences during psychosis and antipsychotic treatment as freely as possible, without imposing any specific questions or directions. This method aimed to capture topics not predetermined by interviewers but raised by participants themselves.

Our findings represent the lived experiences of people who recovered from psychosis with the use of antipsychotics. These reflect both previously identified themes, confirming their presence and importance, and novel important themes. Confirming earlier research, are the experiences with the use of antipsychotics,[42–45] captured in Theme 1. Furthermore, Theme 4: *Impact on identity* is a frequently discussed topic in studies on psychosis and antipsychotics[46–49] and is advocated to receive more attention in the context of antipsychotics, especially in relation to the therapeutic alliance.[50] Our findings confirm the importance of this topic in relation to recovery. The importance of factors beyond (antipsychotic) treatment in recovery, as found in our Theme 5: *Is it truly the antipsychotics?*, is often recognized.[10] The importance of rebuilding meaningful activities and relations for recovery[10,39,51] shows overlaps with our Theme 3: *The pace of recovery.* This theme shows that gaining new experiences in order to know that it is going better is important for recovery. The specific experience of requiring time to recognize improvement is a novel finding. Our Theme 2: *Shifting of realities* is not previously highlighted in research on recovery of psychosis. Our research shows that having lived in and returned from a substantially different reality is a radical experience that permeates the basic experience of being in the world. These altered experiences of self and world are extensively discussed in phenomenological literature on psychosis[52–54] but our research shows that they also seem to play an important role in recovery from psychosis and therefore require attention from clinicians.

Our phenomenological approach highlights the impactful and multi-faceted experience of recovering with antipsychotics, showing that with recovery one's experience of self and the world changes fundamentally. We believe that our findings are especially useful for clinicians in connecting to people recovering from psychosis with the use of antipsychotics and we encourage clinicians to relate to these multi-faceted experiences. Since feeling understood and receiving information in a way they can relate to, is identified as one of the needs of people receiving care for a first psychosis.[55] Connecting with their experiential world—in subject, use of language, and on an emotional level—could make a difference in the therapeutic relationship and recovery process.

To illustrate; classifications and terms like (non-) responders, relapse, (side-)effects, psychoeducation, disease insight, and (non-)adherence reflect clinicians' perspectives. While these concepts are important and can be helpful in clinical and research settings, they do less justice to the perspective of the person in recovery. Exploring beyond the confines of medication or symptoms per se, one might discover the impact of other important experiences. Our research shows the presence of ambivalence about recovery, the importance of identity and self-stigma, difficulties knowing what is true in a fundamentally changed world, and the necessity of time and positive experiences for

people to start perceiving themselves as in recovery. Many of these topics have not—in this way—been linked to the terms used by clinicians, whilst a better understanding of the recovery process has been mentioned to likely improve treatment adherence,[14,56] with all accompanying benefits.[21] Focusing on the lived experience—while "bracketing" our preconceptions—could amplify an empathetic understanding of these often encountered topics in psychosis recovery, and thereby improve therapeutic relationships.

With regard to the strengths of current research, the qualitative phenomenological design provided valuable insights in line with prior qualitative research on this subject. The sample size provided saturation and facilitated in-depth exploration. Our design prioritized the first-person perspective, using a minimal interview structure to capture spontaneous reporting, confirming the presence and importance of some themes, and leading to new themes in the context of recovery with antipsychotics. The application of Levitt criteria[30] increased credibility and confirmability.[33] With regards to limitations, despite efforts to minimize this (bracketing, analyst triangulation), there is always and necessarily subjectivity involved in the interpretation process of qualitative data. Another limitation concerns the transferability of the results. Selection bias will affect representation, as the current participants agreed with the vision of having had a first psychosis and were able and willing to reflect on their experiences. Additionally, over half had a schizophrenia spectrum disorder classification, but not schizophrenia, potentially skewing outcomes toward milder disease and a better prognosis than people with a schizophrenia classification.[41,57–59] However, the topics found in current research may also be experienced by the latter group, even though they might not be able or willing to report on them.

To conclude, the themes described in the current study could provide clinicians inspiration to discuss less obvious aspects of experience concerning recovery with antipsychotic medication. More so, we are confident that exploring the first-person perspective in a way similar to what was done in this research, could lead to a thorough understanding of the all-encompassing, multi-faceted, and ambivalent nature of recovery of psychosis from a first-person perspective, and thereby can help foster better relationships. Making sense of the enormous task faced by people in recovery enables clinicians to guide them compassionately as they navigate their fundamentally transformed position in the world.

Supplementary Material

Supplementary material is available at https://academic.oup.com/schizophreniabulletin/.

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Conflict of Interest

The authors have declared that there are no conflicts of interest in relation to the subject of this study.

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Data Availability

The data we have collected through phenomenological interviewing that support our findings are available on request. The data are not publicly available due to privacy and ethical reasons.

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