

A qualitative approach to explore the service-users' perspectives on antipsychotic medication and its role within the personal recovery framework

Daniël Tromp

1^e begeleider: Nienke van Sambeek – Promovendus Verhalenbank Psychiatrie

2^e begeleider: Prof. dr. Floortje Scheepers – Hoogleraar Innovatie in de GGZ

Psychiatrie – Divisie hersenen

14 juli – 30 september 2022

Abstract

Background: Personal recovery, as defined by the CHIME framework (connectedness, hope, identity, meaning and purpose, and empowerment), is becoming prominent in mental health care policy. The service-users' value placed upon antipsychotic medication within the personal recovery framework is unclear.

Aim: Insight into the individual's perspectives on antipsychotic medication is needed to gain a holistic understanding of the implications of antipsychotic therapy and its interaction with the personal recovery framework.

Method: Using the Psychiatry Story Bank's database: participant-guided stories were used, collected through open, semi-structured interviews. Narratives of 11 participants with a psychotic disorder were analysed using a thematic analytic approach within a phenomenological-constructivist framework.

Results: (1) The role of antipsychotic medication varies in different situations and is dependent on the service-users' needs and circumstances. (2) Service-users desire a holistic approach to treatment with antipsychotic medication as part of a comprehensive treatment package, including the support from professionals. (3) Side effects can have potential life-disrupting consequences; service-user's perceive medication to be ideal in the case of negligible side-effects. (4) Stigma is experienced both inside and outside the mental health services, leading to feelings of devaluation.

Conclusion: This study highlights the great variety in experiences related to antipsychotic medication. Interactions with the personal recovery framework were identified, posing both openings and barriers to processes of personal recovery. In order to strive for personal recovery, it is essential to put emphasis on the service-users' own specific set of needs and circumstances.

Introduction

Antipsychotic medication is the mainstay in the treatment of patients with a psychotic disorder, with an increasing prevalence of use in numerous populations worldwide (1). Effectiveness in the symptomatic treatment of psychotic disorders is beyond dispute. Continued use of antipsychotic medication has been associated with positive clinical outcomes and relapse prevention (2,3). Nonadherence or partial adherence has been associated with poor outcomes, with increased risk of relapse or hospitalization (4–7).

However, clinical outcome, and clinical recovery, which has been the predominant paradigm in psychiatry for the last decades, is now making way for a more service-user based concept of recovery, which has gained foothold in contemporary mental health policy (8–13). There is a clear conceptual distinction between outcome measures defining personal recovery and recovery in clinical practice. The latter generally focusses on reduction or elimination of clinical symptoms, aiming to return to premorbid levels of functioning, or statistical relapse and hospitalisation rates (2,3,14). Personal recovery, by contrast, can occur despite of existent clinical symptoms (14). It entails changing one's attitude to life and illness, with the goal of living a satisfying life within the limitation of one's illness (15). Personal recovery is considered complementary to clinical recovery and represents processes rather than outcomes (13). Leamy et al. described it as an idiosyncratic, multidimensional concept, which focusses on key themes and processes of connectedness, hope, identity, meaning in life and empowerment; acronym CHIME (16). The importance of this conceptual framework of recovery has been widely endorsed (13).

In personal recovery literature, the service-users' value placed upon medical treatment is still source of considerable debate, referring to its ambivalence (17). In order to have a more holistic understanding of the role of antipsychotic medication in personal recovery, it is essential to gain more insight into the service-users' experiences (18).

This study aims to (1) explore the service-user's perspectives on antipsychotic medication, and (2) place these experiences within the framework of personal recovery.

Methods

Setting

This study is part of the "Psychiatry Story Bank" (PSB), a narrative project initiated by the department of psychiatry of the University Medical Centre of Utrecht (The Netherlands). In this project, service-users share their stories through an open,

semi-structured interview. Participants are encouraged to guide the direction of the interview, allowing interviewees to discuss topics that are of personal importance, aiming to acquire the unfiltered experiences on one's own account.

Participants and sampling

Participants for the Psychiatry Story Bank were people that made use of psychiatric services in The Netherlands. Apart from acute crisis, no exclusion criteria were formulated. After signing up, consent for participation was obtained, afterwards the interview was planned and conducted at a place of the participants choosing, often resulting in home visits. All participants provided written informed consent. Interviews lasted 56 minutes on average, were audio taped, transcribed, and stored anonymously in a secured database. Detailed description of data-collection for the Psychiatry Story Bank is provided elsewhere (19).

Using the Psychiatry Story Bank's data corpus, a data set was extracted of interviews conducted between 2017 and 2022. Eligible participants were current or previous psychiatry service users with a psychotic condition and taking or having taken antipsychotic medication on a regular basis at some point in time. Based on the strategy of intensity sampling, the study sample compromised 11 participants after reaching data saturation. The characteristics of the study sample are displayed in Table 1.

Analysis

The data were analysed using thematic analysis in a phenomenological-constructivist framework. Following the guidelines provided by Braun and Clarke (20). The transcripts were assessed based on the prevalence of experiences with antipsychotic medication in the narrative and the level of detailed description. Subsequently, the 'richest' transcripts were examined individually, noting important ideas and experiences described by the narrator to unveil preliminary themes. Extensive coding of the narrative followed, with collation of the codes into themes. Throughout the analysis, reflection and discussion with research team member ensured refining of the specifics of each theme and the analysis.

Results

Four themes were constructed, representing key experiences with antipsychotic medication: *The role of medication: different contributions to different situations*, *The clinicians' disproportionate focus on medication: losing the big picture*, *The significance of side effects: the capacity to disrupt life* and *The impact of medication: feelings of personal devaluation* (see image 1)

Table 1 Participant characteristics

| Characteristics | Participants N = 11 (N) |
|-----------------------------------|----------------------------|
| Gender | |
| Female | 4 |
| Male | 7 |
| Age | |
| 20-40 | 3 |
| 41-60 | 8 |
| Country of origin | |
| The Netherlands | 5 |
| Other (Non-western) | 1 |
| MD | 5 |
| Highest level of education | |
| Secondary School | 2 |
| Vocational education | 3 |
| Professional education | 2 |
| University | 4 |
| Employment | |
| Employed | 7 |
| Unemployed/retired | 2 |
| Volunteer work | 1 |
| MD | 1 |
| Income | |
| Above average | 1 |
| Below average | 3 |
| Minimum income | 6 |
| MD | 1 |
| Partnership status | |
| Partner | 3 |
| No partner | 6 |
| MD | 2 |
| Children | |
| Yes | 5 |
| No | 4 |
| MD | 2 |
| Living situation | |
| Independent | 10 |
| Assisted living | 1 |
| Care history | |
| Single hospitalization | 3 |
| Multiple hospitalisations | 8 |
| Antipsychotic medication | |
| Current use | 9 |
| MD | 1 |
| Past use | 8 |
| MD | 1 |

The role of medication: different contributions to different situations (N=7)

The acute situation: functioning as safety net

Individuals varied in terms of the role medication played throughout their life. In times of turmoil, during a psychotic event, medication was described to function as a safety net, aiding to pave the way towards recovery.

I was admitted to a locked ward, Leponex was brand new. Nowadays they call it by its generic name, Clozapine. From the moment I got that, that's when I started to recover slowly again. (P59)

Stability in prolonged use

Others described it as a tool used to maintain stability. In this sense, medication provided consistency and tranquillity. One participant described it as a tool explicitly needed to regain contact with her displaced child, after the loss as a result of non-adherence due to side effects.

I would like her to come and live with me when I get my own little place. And maybe that will happen. [interviewee] And what is required for that? [participant] that I remain stable, that means sticking to the medication and also work on myself, structure my days. (P29)

Further down the road of recovery: the desire to discontinue

For some participants, who had been using medication for a prolonged time, a desire to reduce or discontinue medication was present. Originating from the desire to experience live without medication or the perceived capability to be able to do without medication, based on a deeper understanding of the nature of the disorder, with more experience in dealing with the disorder and potential triggers. This involved an autonomous process of ambition and devotion towards reduction or discontinuation of antipsychotic treatment. This process was thoroughly considered, with the consultation of a professional, and with acceptance of the possibility of relapse. This was a stark contrast to participants discontinuing medication on account of debilitating side effects or situations with uncontrolled psychic distress, i.e., in an uncontrolled psychotic episode, carried out in a stressful context.

... it is my wish to taper-off, completely if possible. Many do not recommend it, but still, I want to give it a shot. Then I'll know for sure if I can do without. Instead of living with the thought of having could do without. (P67)

An important backup after successful discontinuation

Nevertheless, the use for medication was not completely waived after cessation. A participant described the usefulness during relapse, after being medication free for some time, and acknowledged the helpful role medication can play in time of distress, contributing to a swift return home.

... actually I recovered swiftly, so I could go home, because I've been home for some time now ... that was because I was more experienced, I knew what was wrong with me and I also knew what could help me: the proper medication, rest and regularity. (P34)

The need for medication independent of experience

One participant, who had been working as an expert-by-experience within psychiatric institutions, described the tremendous growth he accomplished in his personal recovery, such as the overcoming of stigma and acceptance of his disorder. This participant stated that despite his advancements in personal recovery, there was still a necessity for medication, describing it in terms of a 'biochemical substitution'.

For me it's a chronic vulnerability, that is evident. And after my latest admission I've come to the conclusion that the only reason I got ill is without my medication or my four-day medication. So, it's something I need biochemically. ... I'm not saying everyone needs it, absolutely not. But I do. (P43)

The clinicians' disproportionate focus on medication: losing the big picture (N=6)

The (other) possibilities in treatment

In both clinical and outpatient care, participants often experienced a narrow vision on treatment from their clinician, with a strong focus on medication, overlooking other potential entry points for treatment such as trauma therapy or mindfulness. Participants described the desire for a more holistic approach to treatment incorporating different forms of treatment, as well as lack of functional and social aspects. This entailed aiding individuals with practical matters such as housing and finance, and entering into a dialogue or presenting a sympathetic ear

Well, the care mental health services offer is simple. You get medication: "do you like the medication yes/no"; "what can we change in the medication"; "do you want extra pills for the side effects yes/no". "How do you feel, how are you getting on." And then, "can we fill in the papers together for the healthcare insurer." That's it. But no other forms of therapy whatsoever. (P67)

It is important for a clinician, that he listens to you, that he takes your story seriously, that it's not like, "have you already had your medication and bye", take a closer look into it. (P35)

Different therapies working together

Notably, the participants described their experience with a certain negative sentiment towards the clinician or the mental health services, but this did not originate from a negative sentiment towards medication. On the contrary, participants underlined the supportive role that medication could fulfil.

So, there is always a link between your brain and what you're experiencing. So, they really looked for it in that. And when you look at the brain function from a pure biological perspective, then you'll look for a solution that fits in that perspective, like medicine. And it really helps me. But there are so many other things that can help. Like looking at the same thing from a different perspective. And for me it's way more interesting when those things can work together (P98)

A trustful doctor-patient relationship: loosening the grip on medication

Throughout the narratives it became evident that participants describing this theme acknowledged the absence of a trustful doctor-patient relationship, portraying it as being shallow, negative, or non-existent. This resulted in feelings of discouragement, not being taken seriously or not listened to.

I've had a psychiatrist who really didn't fit me. I have had several psychiatrists who actually haven't helped me. They prescribed me medication but didn't really offer me the tools to move forward. ... They didn't take me and my hobbies seriously. I like videogames and that kind of stuff, and they only joked about it. I was having a conversation one time and I could only think, I hope this ends quickly, because this doesn't help either. (P34)

Participants looked elsewhere to fill the gap their clinician left in their needs, finding it in relationships with friends or peers, or in the course of time in other clinicians. Once in the company of a clinician who listened and answered their needs, the tide turned. The previous strong focus on medication oftentimes shifted the other way around and participants found themselves in a situation to open conversation about medication. Some participants, with the support of their professional, were able to reduce or quit medication altogether.

Only later I got a good clinician and psychiatrist who really understood me, connected with me, and proposed decreasing medication and so on, so that was a lot better. (P34)

The significance of side effects: the capacity to disrupt life (N=5)

Compromising daily life abilities

A negative sentiment with medication frequently involved an array of distressing side effects that can arise during treatment, such as weight gain, fatigue, sexual dysfunction, the perceived dampening of feelings and the experience of

reduced mental capacity. These side effects affected the participants in different ways. Evidently impacting the person's daily life abilities:

Well, I saw a couch and I wouldn't get off, I was dead tired. That was so bizarre, I wasn't able to do anything, even to get up. (P35)

A life-changing impact

Often these side effects had a more prominent impact than just on the person's daily life abilities. The side effects set in motion a cascade that led to life-changing events, such as the loss of libido resulting in a depression, or a participant losing the ability to take care of her disabled son due to debilitating lethargy. Occasionally this resulted in the participant taking over control of their medication, without consulting a professional, leading to discontinuation and possible relapse.

So, I was given an antipsychotic drug the whole time, but I gained quite a lot of weight because of it. It's not that you see it now, because I've lost weight, but at that time I was twenty kilos heavier. My ex-husband didn't find me attractive anymore, so we argued a lot, and to my knowledge he was also cheating, but I'm not sure. ... That affected my relationship, I just started, because I could take them in separately, the medication, to stop taking them. Tapering off and quitting. Without telling my psychiatrist. ... I quit medication, because I wanted to lose weight, so that my husband would like me again. (P29)

... that's why I got Abilify. And with Abilify depot injection, it went reasonably well. At first the dose was quite high, four hundred milligrams. And it made me feel like I was in a vegetative state, tired and I felt like a zombie. I gained thirty-five kilos in weight. I couldn't continue taking care of my son anymore. (P67)

'Good medication': the significance of side effects

In many cases, medication was perceived by the participants to be ideal in the case of a negligible side effect profile. Interestingly, throughout the narratives, when talking about the definition of good medication, participants predominantly described the importance of absence of side effects, rather than the diminishing or reduction of symptoms.

... I thought it was me, you know, but that wasn't the case. It turned out I just had the wrong medication, for me. Then I got Impromen, a depot injection. Well, that worked great from the start. Actually, I still use it, for nineteen years now. Well, I hardly have any side effects, not that I notice anyway ... for me that determines ideal medication. (P35)

The impact of antipsychotic medication: feelings of personal devaluation (N=5)

Societal views and stigmatisation

In various ways, antipsychotic medication had impact on the participants' self-image. Often with stigmatization at its core, through stereotypes and societal beliefs. Participants were reluctant to share their burden with friends and family for fear of being labelled or mistreated.

...if I had said blood thinners, because I'm a heart patient, then I would have had a relationship [with that person]. Because I said no, they are antipsychotics. No messages anymore. Nothing. Shock effect. I think it's a shame. That truly is an obstacle for me, it really sucks. (P54)

Stigma in the mental health services: being treated as illness

Apart from societal views, stigma was also experienced in the mental health services. Some participants experienced the feeling of being reduced to mere symptoms or the disorder itself, not being treated for the disorder but as the disorder, illustrating the perceived insensitivity of the mental health system to their circumstances. They described the mental health services as 'not personalized' and acting on the base of stigma, causing personal distress and feelings of devaluation.

Just how they reacted to it, even by the caregivers. Like: he is completely off his rocker, just medicate him, and that, in my opinion, is no solution. ... Medication can be, is important, if you get the right medication, but I think that talking with people to help them further, and not just saying, never mind you're not important enough. Because I'm human after all. (P35)

I suspect that I was given a dose that was too high initially, that's why I gained an enormous amount of weight. I would have probably been psychosis free with a lower dose too. So, they just aimed way too high from the start. It's not tailor-made, it's just like, stand in line and take a number. (P67)

Internalising perceived life-long treatment

Others perceived antipsychotic medication as life-long treatment, by self-stigma but also on account of their practitioner, resulting in internalisation. One participant elaborated on receiving a hopeless prognosis by his practitioner, rendering him passive and unmotivated to change.

Well, it was just very difficult to accept that I needed medication. And that I needed to take that medication my whole life. Because when you're twenty years old, that's not something you want to hear. And when you're older you discover that almost everybody takes medication for cholesterol, or blood pressure, or diabetes, or whatever. Everyone has something they need help with. But this felt like a direct hit on my identity or something, on who I am (P90)

...[the practitioners] they diagnosed me with schizophrenia. And they also gave me a prognosis, saying you don't have to think about building a social network or independent living anymore, education is also out of question for you. That really made an impact on me. ... It made me passive. When you can't amount to anything, and they also confirm it. I've been hearing that all my life, caused by other things though, but it makes you passive. Then you won't commit to things anymore, committing to personal development.

Discussion

This qualitative paper examined the lived experience of individuals with a psychotic disorder and their subjective perspectives on antipsychotic medication. Through analysis, four major themes were constructed: *The role of medication: different contributions to different situations*, *The clinicians' disproportionate focus on medication: losing the big picture*, *The significance of side effects: the capacity to disrupt life* and *The impact of medication: feelings of personal devaluation*. In the next section, we discuss the meaning and implications of these results and place them within the context and framework of personal recovery.

The first theme encapsulates the different ways medication can contribute to different situations, determined by the service-user's personal needs. This finding is in line with qualitative research exploring the fully recovered service-user's perspective on antipsychotic medication (21). Medication was perceived to be efficient and supportive in the acute situations of psychosis, similar to findings of other studies (22,23). Participants described medication to function as 'safety net', functioning as an aid to swift recovery, which also applied to participants that had been stable and relapse free for a longer duration of time. During prolonged use, stability emerged as the main contribution, providing the participants with the conditions needed for progress and recovery, similar to findings of a study on long term experiences with antipsychotic drugs (24). Despite stability, some participants described the desire to reduce or discontinue medication, encompassing an autonomous process of ambition and devotion, weighing up the costs and benefits. However, others still acknowledged the usefulness and necessity of medication, playing a vital role in relapse or stability.

The recurrent theme throughout these experiences emphasizes on personal need and preference, dependent of situation, experience, and functioning. In the framework of CHIME this is mainly represented by the superordinate theme of 'Empowerment', encompassing subthemes of self-management, positive risk-taking, control over life and involvement in decision-making. Feelings of powerlessness and lack of choice were commonly described in a study similar to the present study (25). In prescription and usage of antipsychotic therapy, it would there seem important to acknowledge and identify the service-user's personal needs, based on the situation and the individual's functioning and experience level. Routine discussions with long-term users may reveal such needs and thus could act as possible intervention.

The second theme comprised a perceived disproportionate focus on medication in treatment, lacking entry points for other therapies and social and functional aspects. The importance of a broader and more holistic approach to treatment in both clinical and outpatient setting was emphasized by participants in this sample, in line with findings of similar qualitative research (16,26). This entails antipsychotic medication being presented as part of a comprehensive treatment package, supporting the individual's active process of recovery, rather than it being a passive, if not exclusive, component of treatment. Furthermore, studies supporting the crucial role of social and functional aspects in remission and recovery may emphasize the need for its introduction into the dialogue (27–29). The discrepancy in service-users' and clinicians' treatment expectation transpired in the context of lacking professional support. Per contra, a trustful doctor-patient relationship offered the participant headroom for further development and enabled a sense of agency, opening up possibilities to consider reduction or discontinuation of antipsychotic therapy. Research indicates service-users often acknowledge the lack of professional support, and in turn the absence of shared-decision making, when talking about reducing or discontinuation of antipsychotic medication (25,30).

Placed within the framework of CHIME, the superordinate theme of 'Connectedness' is represented. With emphasis on the subtheme 'support from professionals'. The experiences from the current study advocate for a better understanding of the service-users' hopes and expectations of treatment. Previous studies have reported the large differences in expectations of treatment between 'medical practice' and 'patient practice' and the need for an active form of shared-decision making (25,31). A collaborative approach involving both service-users and clinicians may work to align these differences and would further empower the service-user to have control and responsibility in treatment(32).

The third theme illustrated the significance of detrimental adverse effects that commonly coincide with antipsychotic treatment, including weight gain, sexual dysfunction, debilitating state of fatigue and cognitive effects, in line with other studies examining the subjective experience of antipsychotic medication (21,25,31,33–35). Evident was the barrier it could pose to daily-life abilities. Furthermore, this study demonstrated the cascade set in motion by side effects with potential life changing impact at its end, potentially resulting in participants reclaiming control and discontinuing medication on own accord. Also, service-users declared the side-effect profile to be of paramount importance, oftentimes perceiving 'good medication' as determined by a negligible side-effect profile. Thus, identifying and managing poignant side-effects is crucial in order to strive for physical and mental well-being.

Placed within the framework of CHIME, it can be argued that side-effects, if left uncontrolled, can pose a barrier to the superordinate theme 'Meaning in life', impacting on 'quality of life' and 'meaningful social and life roles, and goals'. It would seem important to identify debilitating side effects and intervene in order to prevent possible life-changing events and constrain on one's recovery process. Furthermore, studies have demonstrated patients reporting difficulty communicating their concerns about side effects of antipsychotics with a professional, stressing the importance of 'support from professionals' (25).

In the fourth theme it became evident how antipsychotic medication resulted in feelings of devaluation. Experiencing stigma both in and out of the mental health services, it became clear that participants experienced stigma on the level of medication.

Placed within the framework of CHIME, superordinate theme 'Identity' represents these experiences. Posing a probable barrier to 'rebuilding/redefining positive sense of self' and 'Over-coming stigma', encompassing self-esteem, acceptance, self-stigma, and stigma at a societal level. Similar to a study on the experiences of psychotropic medication, explicitly specifying stigma on psychotropic drugs (31). Stigma has been reported as a prominent barrier in recovery and predicts low self-efficacy and poor coping in individuals diagnosed with schizophrenia (36,37).

Several limitations emerged during the execution of this study. Firstly, the Psychiatry Story Bank is an ongoing project which enables researchers to acquire extensive data for qualitative research purposes without having to go through laborious data-collection. However, due to the nature of using open-ended pre-recorded interviews, depth of data, as described by Braun and Clarke, can be impaired on certain specific topics (38). In relation with this study, participants often mentioned medication and experiences with medication briefly or incomprehensively, straining the objectives of thematic analysis in this regard, calling for more a more structured and focused method of data-collection.

Secondly, participants in this study consisted principally of long-term service users, often with decades of experience with the mental health services, as well as with the dealing of their own mental illness. Results from this study are therefore not necessarily generalisable to service-users with less protracted experience. Furthermore, described experiences went as far back as 40 years into the past. In the everchanging field of psychiatric care, this data may be outdated and not representative of contemporary mental health services state of affairs. This calls for more attention towards lived experiences at present time.

This study illustrates the great variety in experiences related to antipsychotic medication and the different ways of possible interaction within the personal recovery framework. It underlines the ambivalence that is expressed by the service-users and the possibility of both promoting and inhibiting processes of personal recovery.

In a mental health system, which is adjusting to adopt personal recovery outcomes it is essential to put emphasis on the service-users' own specific set of needs and circumstances. In light of this, it may be useful for clinicians to initiate an open, collaborative dialogue with service-users around how antipsychotic medication may fit with their hopes and expectations for treatment and try to identify which aspects stand in the way of their journey to recovery.

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