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ORIGINAL ARTICLE

Antipsychotic treatment: experiences of fully recovered service users

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Abstract

Background: There is lack of long-term controlled studies evaluating treatment effects of antipsychotic medication. A complete investigation should include the service user perspective.
Aims: To investigate experiences of clinically recovered service users of antipsychotic medications during and after a first episode of psychosis.
Method: We used a thematic analytic approach within an interpretative-phenomenological framework. 20 clinically recovered service users were interviewed.
Results: Themes: (1) *Antipsychotic drugs reduce mental chaos during the acute phase*, (2) *Non-stigmatizing environments were perceived to increase chances of successful use*, (3) *Antipsychotic drugs beyond the acute phase – considered to compromise the contribution of individual effort in recovery*, (4) *Prolonged use – perceived to reduce likelihood of functional recovery*, (5) *Antipsychotic medication was considered as a supplement to trustful relationships*.
Conclusions: Acute phase antipsychotic treatment was mostly perceived as advantageous by this sample, who was in clinical recovery. However, costs were often seen as outweighing benefits beyond the acute stage. Findings clearly emphasize the need for a collaborative approach to be integrated across all phases of care. This study underscores the need to investigate sub-group differences with regard to long-term antipsychotic treatment.

Keywords

Recovery, clinical recovery, psychosis, first episode psychosis, antipsychotic, antipsychotic medication, service user, first-person accounts

History

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In psychosis, standardized clinical treatment guidelines generally recommend that individuals should be treated with antipsychotic medication in the acute phase as well as throughout the protracted phases of maintenance and recovery (APA, 2006; Kreyenbuhl et al., 2010; NICE, 2014; Sohler et al., 2016). Antipsychotic medication has unequivocally proven effective in acute and short-term treatment (Bola et al., 2011; Leucht et al., 2012b). However, there is a lack of long-term, systematic double-blind controlled studies using clearly defined samples in terms of illness type, severity and duration (Adams et al., 2013; Sohler et al., 2016) evaluating treatment effect. This has resulted in a call for large-scale independent trials (Bola et al., 2011; Leucht et al., 2012a; Saha et al., 2016) in order to create a new and improved evidence base to sufficiently understand the long-term benefit/risk balance of antipsychotic drugs for different sub-groups of service users (Sohler et al., 2016). There is also a need for systematic investigations of different sub-groups of service users' perspectives on antipsychotic medication use throughout the course of illness. Such perspectives are necessary to develop clinically relevant hypotheses for the suggested large-scale trials, and to illuminate implications for different sub-groups of individuals.

Representing a step in this direction, this exploratory study aims to investigate clinically recovered service users' perspectives on the use of antipsychotic medication during and after a first psychotic episode. This was done by interviewing a sample of 20 first-episode psychosis service users in clinical recovery (Davidson et al., 2008), operationalized as the fulfillment of strict criteria of both symptomatic (Andreasen et al., 2005) and functional (Hegelstad et al., 2012) remission throughout the past year. Between 9 and 21% of service users with FEP achieve clinical recovery (Jaaskelainen et al., 2013), making this a highly relevant sub-group.

Method

We used a thematic analytic approach (Boyatzis, 1998; Braun & Clarke, 2006) within an interpretative-phenomenological framework (Gadamer, 1989; Heidegger, 1996). In this study, the interpretative element implies that data were both generated from a reflexive dialog between participants and researchers and involved a member checking procedure throughout the interview. The phenomenological element

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suggests that significant knowledge was collected from individuals with lived experience of mental health problems, and that the central aim was to discover and interpret the meaning of such experiences within their broader contexts (Fossey et al., 2002). This study was approved by the Regional Ethics Committee in Norway (2013/1246-REK sør-øst C). Informed consent was obtained.

Sample and recruitment

The sample was recruited from the TIPS-1 study ($N = 281$) and the on-going TIPS-2 study ($N = 400$ approximately), two naturalistic follow-along FEP studies in south-Rogaland, Norway including individuals with FEP from 1997 to 2014. Detailed descriptions of the inclusion criteria and methods have been published elsewhere (Joa et al., 2008; Stain et al., 2013).

Individuals who were included in the study met the following criteria: living in the catchment area (Rogaland county); age 15–65 years; meeting the DSM-IV criteria (as measured by the Structured Clinical Interview for the DSM-IV Axis 1 Disorders) (First et al., 1995) for a first episode of schizophrenia, schizophreniform psychosis, schizoaffective psychosis, delusional disorder, brief psychosis, affective disorder with mood incongruent delusions, or psychosis not otherwise specified, and also from 1 August 2008 substance and alcohol-induced psychosis (excluded for the purpose of the present study); being at the time of enrollment actively psychotic as measured by the Positive and Negative Syndrome Scale (PANSS) (Kay et al., 1987); not previously receiving adequate treatment of psychosis (defined as antipsychotic medication of 3.5 mg haloperidol equivalents for 12 weeks or until remission of the psychotic symptoms); no neurological or endocrine disorders related to the psychosis; understanding and speaking one of the Scandinavian languages; an IQ over 70; and being able and willing to sign an informed consent. At inclusion participants agreed to baseline assessment, and follow-up after 3 months, and 1, 2, 5 and 10 years.

In this sub-study participants were recruited consecutively at 2-, 5-, and 10-year follow-up sessions. Here, the TIPS team conducted a screening process based on the criteria for clinical recovery. 27 eligible candidates were contacted; of these, four people refused the study participation and three were classified as non-recovered (subsequently after the actual interview), due to only 50% part-time work. Sample size was decided on the basis of stability of findings, reviewed after 15 and 17 participants (Hill et al., 1997). We stopped recruiting after 20 participants (one participant from TIPS-1 and 19 participants from TIPS-2), because we considered the last three interviews as not contributing any substantially new information.

The study sample comprised 10 females and 10 males, all ethnic Norwegians. At the interview time-point, they were all living independently and were in full-time employment or education and average years of education after mandatory school (equals high school level) was 1.15 years (range 1–4 years).

At baseline, participants' clinical diagnoses were affective disorder with mood incongruent delusions ($n = 5$); psychosis not otherwise specified ($n = 8$); delusional disorder ($n = 3$); schizoaffective disorder ($n = 2$); and brief psychotic disorder ($n = 2$). The average age at inclusion was 25.8 years (range 17–58 years) and median duration of untreated psychosis was 12 weeks (average 26.5 weeks; range 0–156 weeks). At baseline, sub-study participants showed an equal distribution and severity of psychosis symptoms were compared to the rest of the TIPS-1 and TIPS-2 study samples. The duration of untreated psychosis was significantly lower among sub-study participants. They scored significantly higher on frequency of social meetings and quality of social relations (as measured with Lehman's Quality of Life Interview (Lehman, 1996).

At baseline, all participants were recommended to use medication, although seven never used antipsychotic drugs. They described their choice to decline drug treatment as carefully deliberated, with their reflections related to declining thus considered relevant to our study aim, warranting the inclusion of these participants' statements in our analysis. For most of those using medications, initial exposure to medication took place in an inpatient setting (eight out of 13). For the remainder of participants, their initial exposure was received in various outpatient settings. 12 participants used low-dose (range 0.04–1.0 defined daily dosage (DDD) (WHO, 1996), second-generation antipsychotic medication, mostly Olanzapine, during the first year of treatment. One participant used Perfhenazine (0.5 DDD). Eight used medication after one year of treatment and six at the time of the interview. 13 were interviewed at 2 years follow up sessions, 6 at 5 years and 1 at 10 years.

Measures

Symptom remission was defined in accordance with international standardized criteria (Andreasen, 2006): no score > 3 for the past 6 months on either of the following PANSS items: P1 (delusions), P2 (disorganized thought), P3 (hallucinatory behavior), N1 (affective flattening), N4 (passive social withdrawal), N6 (lack of spontaneity), G5 (bizarre posture) or G9 (unusual thought content). Individuals were categorized as non-remitted if they reported any relapse, defined as deterioration of symptoms scored > 3 on the relevant PANSS scales, during the previous 6 months.

Functional remission was measured by three of the Strauss-Carpenter Level of Function Scale (Strauss & Carpenter, 1977) subscales measuring independent living, role functioning (work, school or full-time homemaking), and social interaction. A score of 0 indicated very poor functioning, while 4 indicated adequate functioning for the total period of the previous 12 months. A score of 4 in all three subscales was required to indicate overall adequate functioning.

Clinical recovery was operationalized as a single variable of ''yes'' for all patients who met criteria for both symptom remission and adequate functioning.

Interviews

Interviews were conducted between June and December 2014. A semi-structured interview guide was developed by the authors in line with the recommendation in Miles et al. (2013) (p.25), based on the literature on factors facilitating recovery, including antipsychotic medication (Beck et al., 2012;

Bellack et al., 2007; Davidson et al., 2001; Leamy et al., 2011; Leucht et al., 2012b) and collaboration between researchers and two clinically recovered service users. The following focus areas guided the interview: (1) person-specific factors; (2) environmental factors; and (3) treatment-related factors. Each theme was introduced with an open-ended question, for example, *How would you describe the treatment you have received, from the day you got difficulties and until today?* The questions were followed-up depending on how much the participant elaborated. We tried to encourage participants to relate their experiences to different contexts, asking questions such as, *can you please elaborate on how the antipsychotic medicine helped you in the acute phase?* or *can you tell me a bit more about the link between feeling safe and adherence?* To capture topics not adequately covered by the interview, participants were invited at the end of each session to provide any information which had not yet been elicited. Pilot interviews were conducted with two clinically recovered service users. The first author conducted all interviews, performing 17 of these at Stavanger University hospital, and the remaining three in participants' homes (Mean duration: 51 min; Range: 37–76 min). Interviews were audiotaped and transcribed verbatim for the purpose of analysis.

Analysis

With a particular focus on experiences concerning antipsychotic medication, semantic analysis employed a meaning condensation procedure (Braun & Clarke, 2006) involving six-steps presented in Table 1. To strengthen the credibility of the study, three of the researchers conducted the six-step procedure independently. Further, during three collaborative meetings the same researchers compared their interpretations, agreed on themes with accompanying quotes, and validated the findings by consensus decision (Hill et al., 1997).

Table 1. Steps of text condensation.

1.	Becoming familiar with the data through thorough reading of the transcribed interviews, forming a main impression of the experiences of the participants, and identification of potential important themes. A theme was defined as a verbalization capturing an important element of the data in relation to the research question, representing a patterned response in the data set.
2.	Generating initial codes, which were defined as the most basic segments of the raw data that could be assessed in a meaningful way regarding the phenomenon.
3.	Searching for and developing candidate themes and sub-themes. Remaining codes were set aside at this phase in a separate category for the purpose of being further analyzed and incorporated when appropriate.
4.	Reviewing themes to develop a coherent thematic map and considering the validity of individual themes in relation to the data set.
5.	Defining and naming themes: Further refining and defining themes, identifying the essence of themes, identifying subthemes and summarizing the contents of the main themes into what each researcher considered to best represent participants' experiences. When our refinements no longer added substantially to the themes, the analytic process was closed.
6.	To determine the relevance of a particular theme we both counted the frequency of the relevant meaning units combined with our interpretation of how central the theme was perceived to the recovery process.

The collaborative meetings had a particular focus on steps four to six presented in Table 1. To overcome possible disagreement in the analytic process, we agreed on the following decision rules in the preparatory phases of the study: (1) Resolve minor disagreement utilizing the principle of parsimoniousness (i.e. Occam's razor: *when you have two competing theories that make exactly the same prediction, the simpler one is the more likely*). (2) To resolve major disagreement we applied (i) an inductive principle using the raw data as a compass, aiming to select the descriptions most closely reflecting the experience of the phenomena at issue. (ii) Further, we applied the principle of the best argument as described above. Inter-rater agreement between researchers was tested (Pope et al., 2000) and assessed as high.

Results

The textual analysis resulted in five related themes. In sections where data for all participants ($N = 20$) are included this will be referred to as the full sample. However, the majority of analysis is focused on the 13 individuals with experiences of using antipsychotic drugs.

Antipsychotic drugs reduce mental chaos during the acute phase

Most participants received low dose, second-generation antipsychotic medication during the acute phase, and experienced it as necessary to stabilize mental chaos and reduce stress. Driven by a state of terror and anxiety, they described a willingness to do almost anything to make psychotic symptoms vanish, describing this as a major motivation to accept treatment with medication. The provision of detailed information about antipsychotic medication prior to commencement and the establishment of trust between client and professionals were described as increasing the likelihood of successful use, and enhancing participants' subjective experience of control.

> They were kind and gave a solid impression at the ward. When they recommended that I should use pills I thought that was okay. The comprehensive information made me feel safe. I took them. I think the drugs did me good by stopping chaotic thinking.

Non-stigmatizing environments were perceived to increase chances of successful use

Many participants (full sample) equated longer term antipsychotic drug use and psychiatric ward admission accepting the role of being a ''psychiatric patient,'' which in turn triggered an expectation of stigma from others, as well as self-alienation. This was described as one of the main causes why some participants turned down the offer to use antipsychotic drugs. However, although there were mixed experiences with being hospitalized, many of those hospitalized for longer periods of time described a non-stigmatizing, inclusive atmosphere, which reduced this sense of stigma and self-alienation. Such an atmosphere appeared to increase adherence and willingness to accept the use of antipsychotic drugs.

Many also described their social network as having similar non-stigmatizing characteristics, again facilitating the use of antipsychotic drugs.

> It must be a place where you can be yourself. Most others used medication and it was okay to have a mental illness. You did not feel like an alien. For me it was a big turning point – before and after the ward. It made it easier to follow and commit to the treatment.

Antipsychotic drugs beyond the acute phase – considered to compromise the contribution of individual effort in recovery

Use of antipsychotic medication beyond the acute phase was often described as interfering with the perception of individual effort as vital to obtaining recovery. Using medication made it difficult for participants to evaluate the effect of their personal contributions, thereby reducing their experience of individual influence and accountability in recovery.

> They had little or no effect, and several side effects. Once I started psychotherapy I felt it helped. Whether it is the drugs or whether it is receiving psychotherapy, or a combination, I'm not sure. It is not easy to separate out what is your own contribution when you are using pills. Makes it kind of blurry. I did not feel that this little pill once a day would make a big difference to me. Nor was it that I had to work for it in other ways. I am skeptical of these types of medication. I rather think you have to do something inside your head. I didn't feel that pills were a solution.

Prolonged use – perceived to reduce chances of functional recovery

Physical and cognitive side effects

Most participants discontinued their anti-psychotic medication shortly after the acute phase, due to considerable physical and cognitive adverse effects such as fatigue, experience of reduced mental capacity and substantial weight gain. Participants described feeling inclined to discontinuing their medication, sometimes against medical advice, due to their sense of personal perseverance, determination and their experience of having withstood their severe acute phase symptoms. Also, participants said they educated themselves about beneficial and adverse effects as well as about secure discontinuation. They described this process as allowing them to feel more aware and safe in their decisions to decline antipsychotic medication, or to terminate use.

> When I was given medication, I gained 15 kilos in three months. I didn't want to continue further down that road. I conveyed successfully that I ought to receive smaller doses, but did not feel it helped. It was at that point I decided to do this myself. I read a lot about antipsychotic pills, talked to my mom and told her I wouldn't take them anymore. My mother and doctor suggested that we should try another type, but then I said: ''Pills can't fix this alone, they don't solve everything. And if I can manage this without pills I'd rather do that.''

Compromising daily life functioning

As their psychotic symptoms abated, most participants experienced functional adverse effects of medications, which compromised daily life functioning by preventing them from participating in ongoing meaningful activities such as school, work and physical exercise. Adverse side effects were described as particularly limiting, causing many to quit antipsychotic drugs despite still experiencing residual symptoms of psychosis.

> I used them for three weeks. I felt very sleepy. I thought: ''This can't go on, I have to keep up my physical exercise. I can't have my exercise ruined by this medicine.'' Then I thought: ''I can't take this medicine because it makes me weak.'' Those days when I used the medicine I felt very weak, and when I stopped using them, I felt physically normal again. . . Although I heard voices during this period I decided to stop. It was hard but after a while the voices vanished. When I think about it today I think it was the right choice for me.

Antipsychotic medication was considered as a supplement to trustful relationships

Many participants (full sample) described having had well-developed social networks prior to FEP. They believed that problems, including psychological ones as related to social situations and perceived maladjustment (e.g. social withdrawal as a result of bullying, social anxiety and lack of coping), were in turn described to have relational solutions, e.g. support from family, friends and psychotherapy, which was thought to improve resilience and build coping strategies. A perceived disproportionate focus on antipsychotic drugs from professionals was described as being in conflict with their idea of recovery as a social process, resulting in resistance, mistrust, and ultimately non-adherence.

Social network

> We talked about everything. Gave each other advice. The important thing is to open up to friends and speak out. That has helped me a lot. There has been a lot of support from them. They have helped me get started on the path that led me to where I am now. The person I am today, I've built up through other people. I've found myself, what I like, and what I don't. I know what I'm comfortable with now.

Psychotherapy

> I think therapy was beneficial. Not so much the drugs. The overly vast focus on drugs made me angry. My problems

were not about that. What worked was when I told my therapist how I was doing, and he managed to tell me in another way why I felt that way. If you open up and listen, you may understand why things have been as they have. I acquired a different perspective. It is easier to hear from someone who knows more about it. But you have to want to hear it. I became more and more and more willing to dedicate myself to therapy.

Discussion

With emphasis on subjective and contextual perspectives, the aim of this study was to investigate the perspectives on antipsychotic medication of service users in clinical recovery following a first episode of psychosis. The analyses resulted in five related themes. On a superordinate level, participants seemed to assess antipsychotic medication as a significant contributor to symptomatic remission during the acute phase of illness. Functional recovery beyond the acute phase was, however, primarily attributed to individual efforts and social influences, and less to medication.

Relevance for the ongoing debate on antipsychotic drugs, and possible clinical implications

This study highlights a great variety of experiences related to antipsychotic medication, ranging from seeing drugs as imperative to achieving and maintaining recovery, to considering medication and side effects as a major barrier to functional recovery. Although the study findings do not present a final yes or no answer to the question of whether the costs of antipsychotic treatment outweigh the benefits, we would like to highlight the noticeable shift in perceived usefulness between the acute phase and later stages of illness. The latter specifically relates to processes of functional and social recovery, which is achieved by 9–21% of service users (Jaaskelainen et al., 2013), including the study sample. These processes are often more protracted, and require more tenaciousness, compared with attainment of symptomatic remission (Liberman & Kopelowicz, 2002). These findings are in line with previous findings of substantial subgroup differences in the course and outcome of psychotic illness (Andreasen, 2006; Harrow & Jobe, 2013; Wunderink et al., 2013), advocating the need to better differentiate clients who are stable and symptom free from others with persistent positive symptoms. Such an approach could be preventive, especially in relation to long-term use, where the potential for serious side effects are greater (Moncrieff, 2015). Due to the lacking long-term evidence base (Sohler et al., 2016) this type of evaluation is today primarily dependent on clinical judgment, which may be good if the clinician is good (Murray et al., 2016). It does, however, reduce opportunities for a systematic approach and standardized care. In this regard study findings, particularly with regard to long-term functional aspects of recovery, echo previous findings (Bola et al., 2011; Leucht et al., 2012a; Saha et al., 2016) in their call for large-scale independent trials in order to create a new and improved evidence base to sufficiently understand the long-term benefit/risk balance of antipsychotic drugs for different sub-groups of service users (Sohler et al., 2016).

Our findings further support the development of a system-wide implementation of safeguards and checkpoints to frequently monitor clients' experiences and wishes related to antipsychotic use. Consistent with previous research (Borg & Kristiansen, 2004; Dixon et al., 2016), a collaborative approach involving both care providers and service users may work to prevent reluctance and non-adherence and may also provide key information in both directions as to the appropriate dosage and duration of use. Further, in order to reduce service users' anxiety and negative prejudice associated with receiving a psychiatric diagnosis and antipsychotic medication (Hamilton et al., 2014; Kleim et al., 2008; MacDonald et al., 2005), our findings, in line with previous research (Perkins et al., 2006), suggest that clients need to be well informed before initiating antipsychotic treatment. Information appears to best facilitate successful use when delivered in a manner to support and sustain perceptions of self-agency in recovery. This entails presenting antipsychotic treatment as one of many tools supporting the person's active recovery processes, rather than as the main passive, if not exclusive, way to recovery. Also, it seems beneficial to focus especially on phase-specific needs, e.g. by linking successful antipsychotic treatment to the potential achievement of social and sustainable goals and functional aspects of recovery. Consistent with previous research, findings of the present study also indicate that re-establishment of social relationships and perceived social inclusion are of particular importance for early recovery (Davidson et al., 2001; Windell et al., 2012, 2015). Such information should be presented as soon as possible in the treatment course, as many participants reported discontinuing medication at a very early stage.

Previous investigations reveal that a substantial number of FEP individuals have less severe psychosis diagnosis then those fulfilling criteria of core schizophrenia (Jaaskelainen et al., 2013). Currently, guidelines also include these individuals in their recommendations for whom antipsychotic medications should be utilized, including the longer term maintenance and recovery phases (APA, 2006; Kreyenbuhl et al., 2010; NICE, 2014; Sohler et al., 2016). For this sub-group of individuals, the current study findings seem particularly relevant, adding to the body of evidence on why behaviors of non-compliance are displayed, both in the short-term and over the long-term. Findings justify a further investigation of these issues using generalizable inferential statistics, reflecting the explicit debate in the NICE guidelines (2014), regarding the option of withdrawing antipsychotic medication after an episode of acute psychosis. A particularly important point may be how antipsychotic drug use beyond the acute phase affects individuals' perceptions of self-agency. This study also underlines the need for identifying which sub-groups benefit from various antipsychotic treatment algorithms or non-pharmacological treatment strategies. Over time, this may lead to treatment being more responsive to phase-specific needs.

Limitations

Findings are context dependent to the participants and setting in which the study was conducted. This study was performed

in an early intervention area, meaning that participants received an extensive standardized treatment package. This may decrease generalizability to populations not covered by this type of health care. Also a high percentage of participants have episodic psychotic conditions and only two participants fulfilled criteria of core schizophrenia (schizoaffective disorder) at the time of the interview. The chances of becoming and remaining asymptomatic is greater for individuals with short-term and limited psychotic conditions, and it is expected, when using clinical recovery as inclusion criteria, that recruitment will identify mainly participants with predominantly benign courses and outcomes. This does not, however, compromise the validity of the relevant findings, but particularly decreases generalizability with regard to the most severe and prolonged psychotic conditions, such as schizophrenia. Finally, although most service-users were interviewed in conjunction with their 2-year follow up session, participants were interviewed at different follow ups (2 years, 5 years and 10 years), which means there is heterogeneity present in the study sample with regard to illness history.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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